

“Becoming people to each other”: How practice and meaning intersect in the delivery of aged care and disability support

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A thesis submitted in fulfilment of the requirements for the
degree of doctor of philosophy

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University of Tasmania

August, 2016

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Declaration of originality

This thesis contains no material which has been accepted for a degree or diploma by the University or any other institution, except by way of background information and duly acknowledged in the thesis, and to the best of my knowledge and belief no material previously published or written by another person except where due acknowledgement is made in the text of the thesis, nor does the thesis contain any material that infringes copyright.

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Authority of access

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Publication related to this thesis

Banks, Susan (in press, 2016). "Knowing me, knowing you": Disability support worker as emotional mediator?", *Sexualities*.

Statement of ethical conduct

The research associated with this thesis abides by the international and Australian codes on human and animal experimentation, the guidelines set by the Australian Government's Office of the Gene Technology Regulator and the rulings of the Safety, Ethics and Institutional Biosafety Committees of the University.

This thesis is dedicated to the people in my study who live care and support
and who let me see and hear about their lives.

Abstract

This Australian research investigates how practice and meanings of care intersect in the delivery of support to people with disability and the frail aged. There is ambivalence surrounding 'care' in the literatures on ageing and disability: constructions of care differ between these fields. In the field of ageing, care tends to be understood as love and altruism, an extension of the self to give ease to another. For disabled people, care is associated with control, institutionalisation, cruelty, and abuse. Despite these differences, found in the literature, the provider organisations, physical practices, and even the individual workers in aged care and disability support frequently overlap. Furthermore, workers and clients from both fields share a sometimes stigmatised position, hidden in backstage settings, engaged in 'dirty' work, and socially and economically marginalised. The voices of workers are rare in the literature, as are studies that combine an empirical focus on meaning and practice.

This study used interviews, observations and visual methods with aged care and disability support workers, and with clients. Participants worked or lived in residential facilities, in group and supported accommodation and in private houses. The thematic analysis explored presentation of self, worker and client practices, perceptions of the other and how these elements coalesce in the service encounter. The co-creation of a competent self was revealed as being central to the meaning and practice of care with emotion work enabling both participants to find ways to co-produce one another's presentation of self. Such co-creation is only possible when the actors (workers and clients) recognise one another on the levels of love, rights and solidarity, and relies on emotion work. An ideal encounter between a support worker and a disabled person creates the possibility of (mutual) recognition. But interactions can also undermine individuals' presentation of self and damage opportunities to experience recognition. I argue that all levels of recognition—love, rights and solidarity—must be present in a support interaction in order for the participants to experience enabling and satisfying working relationships. Further, recognition must be mutual. The research findings have implications for the wellbeing of workers and clients, the responsibilities of

community and facility provider organisations, for future training of workers, and for policy.

Key words

disability support, aged care, emotion work, recognition theory

Acknowledgements

I came to this doctoral project after many years in research and editing work; that was absorbing and rich, but there had been little time for focused contemplation and single-minded pursuit of ideas. The opportunity this project gave me to delve deeply, to read and think widely, to explore and to imagine has been a wonderful luxury. For that luxury there are several people and entities to thank.

I would like to thank the university for the opportunity, for the scholarships that were essential, and for the tutoring and other work that sustained and enlightened me.

In the School of Social Sciences, my supervisors, Dr Emily Hanson and Professor Douglas Ezzy managed to both let me get on with it, and provide essential navigational advice. I had numerous useful and re-creating conversations with Brendan Churchill, as well as plenty of just happy times. My room-mates Lisa Denny and Jen Ayton created opportunities for reflection and wild mental venturing which were thrilling, as did Dr Felicity Picken. Dr Anne Coleman has been a sounding board who 'got it' time and again. Thank you as well to Professor Maggie Walter (PVC) who taught me valuable lessons about identity and strategy, and to Professor Jan Pakulski, whose lectures and tutorials were inspiring, and who asked difficult questions I needed to answer. Denise Jones and Bronwyn Peters kept the wheels in motion—thank you. Dr Suanne Lawrence has been clear-eyed and generous. Outside this university, I want to express my eternal gratitude to Lynne Simpson at QUT who really brought me into research and taught me essential lessons.

Before and beyond the university, though, my parents Max and Doris Banks sowed the seeds: they have each lived the 'life of the mind' and it looked good

to me. While sociology might seem a far cry from their expertise in the physical sciences, there are many things in common and their interest and ideas (as well as their love) have been essential. The same is true for my brothers and sisters, all of whom have collaborated in this project in various wonderful ways.

Most essentially, though, my sons Walter and Jack brought their own disciplines and ways of thinking and their wonderful loving enthusiasm and generosity to my contemplation and writing. These are conversations I can never have enough of. And my 'dance partner', Peter, was an invaluable sounding board who brought a very different perspective to the work, supported me in all sorts of ways and remained steadfast and engaged.

Thank you all.

Chapter 1.

Introduction

I had the story, bit by bit, from various people, and, as generally happens in such cases, each time it was a different story.

Edith Wharton, *Ethan Frome* (1911)

There are many stories of care and support. There are the personal stories of those working in aged care and disability support, and the stories of their clients. There are public stories: the depictions of the work and workers in the media, in policy and in the literature. I wanted to see what threads these stories shared. Is care an expression of love and altruism, an extension of ourselves to give ease to another, or is it a straightjacket, applied to control unruly bodies, emotions and minds? What is going on when ease or support is given not to a loved intimate but to someone we visit as part of a job? And why does care go wrong—why are some of the stories of care about cruelty, narrow control, institutionalisation and abuse?

Background

Several years ago, I was working on a research project about dementia care. We visited nursing homes (residential aged care facilities) at shift change and invited the staff to complete a survey to see what they knew about dementia. While they were doing the surveys, we talked, and I saw what was going on. Residents would come into the nurses' station and ask for things, or want a hug, or be weeping because they wanted to leave. A very elderly lady came and

asked whether someone could help do up her cardigan buttons as her father, who usually helped her, had gone out. The care workers smiled, or frowned, helped with buttons or drinks, put an arm round a resident and steered them away from the door, helped them with the suitcases they had packed, and gave and accepted kisses. I saw them working—what they did and how they were with residents. I knew from talking to them and watching them working that they had a broad array of skills, a lot of knowledge and—with some exceptions—were engaged with the residents. They cared about them, paid attention and accepted their reality.

But when we looked at the dementia knowledge survey results, what I'd seen and heard was not there. First of all, the care workers (extended care assistants and personal care assistants) did not do very well on the tests; it appeared that they did not know much about dementia. And secondly, there was nothing in the results that expressed the personal aspects of their role—the skills and knowledge they had developed while working with individual people with dementia, or how they were with the residents. The picture of care workers we saw in the surveys was not reassuring: it was different from what I had seen and it was inadequate.

At the same time, I had the task of finding images to go in our reports and presentations, searching news archives and online image banks. Here, too, there were differing stories, as if playbills for two different plays. Images were either sentimentally unrepresentative or accompanied news stories about incompetence or cruelty. My interest in what was going on increased. I started to explore how 'care' was depicted elsewhere. Since the work had much in common, I searched for the terms "aged care" and "disability support". The images I found fell into distinct categories. On one hand, there were images that positioned workers as patrons and recipients as supplicants: an old gnarled hand clasped by a much younger, stronger hand; a young hand on an old

shoulder; a caring look from a standing, air-brushed young woman to a seated or stooping person, who looked grateful. Older and disabled people were being positioned as weak, of lower status, and passive (albeit sometimes very cheerful-looking). In this category, while an idea of 'care' was being depicted, there was an overtone of unequal power. Notions like 'as cold as charity' came to mind. The images also evoked the particular tone used when an older or disabled person is addressed using patronising terms or phrases like "Dear", and "How are we?".

Stories of a different sort of unequal power were told in the alternative images, of bruised limbs, of abused residents with black rectangles obscuring their identities and of care or support workers and nurses being charged with abuse. There was a great deal of material that portrayed care and support workers as cruel, or simply incompetent, and clients as their helpless (sometimes impotently angry) victims. I wondered what impact might such depictions have on the insiders, the workers and clients involved in care and support.

And there was something missing: these stories, told from the outside, neglected some of the ways of knowing and being I had seen in nursing homes, just as the survey had. How might care be depicted if the stories were told by insiders? And what would a richer depiction of this world look like?

My doctoral research seeks to bring the voices of the insiders into the open. I used qualitative methods to address the question of *how practice and meanings of care intersect in the delivery of support to people with disability and the frail aged*. Within that, I was interested in how practice shapes meaning, how clients shape practice and meaning, and how the work, the worker and the recipient are depicted in public documents.

Working ethnographically, and guided by Goffman's (1959/1990) dramaturgical approach, I interviewed and observed some of these actors, both in the backstage where most support work takes place, and in some frontstage

settings. I asked them about the roles they played, what they brought to those roles, and about the costumes, props, stages and scripts. They told me about motivation, about successes and failures, about how they viewed care, and about the other actors in the play. Workers talked about clients, about colleagues and about management; clients talked about workers, about other clients and about management. I observed subtleties of interaction—engagement, power-plays, and small and large signs of trust—that also told how meaning was created or sustained.

Analysis of the data showed that several things bound these players. Firstly, that clients were experiencing limitations was obvious; yet workers too revealed the ways in which their own lives and life chances had been shaped by accidents, illnesses and losses. Further, the scope of participants' agency was not contingent on their formal role; workers and clients were being buffeted by structural forces that marginalised and demeaned them. They resisted. Evident in their moment-to-moment performances in service interactions was a desire for their competent self—a self that was congruent with their own sense of themselves—to be both presented and acknowledged.

The study's focus was firmly on meaning for the people involved. Nonetheless, national and organisation-level policy and procedures frequently appeared in the data as forces shaping the care and support experience. Some implications for policy and for organisations are therefore discussed.

Labels

The terms 'worker' and 'client' are used in the present study. Like me, participants in the study had some difficulty with selecting the right terms for one another. 'Workers' was fairly straightforward, but a range of labels was used for younger and older people with disabilities. In several instances,

provider organisations had decreed a particular term, which workers only sometimes remembered to use. 'Clients', 'consumers', 'recipients', 'participants', 'people we work with', 'residents', 'the guys' were all used. The people to whom these labels were attached were similarly a little unsure about what to call themselves. Each term comes with connotations. The most common 'formal' terms used were 'residents' and 'clients'; I decided to accept Vic's rationale for the choice: *"Cause like, as my parents, my dad and my brother are lawyers, client is not a derogatory term"* (Vic, works in disability residential facility).

The thesis structure

This chapter has introduced the motivation for the present study, as well as the key informants, methodology and methods, and an outline of the results.

Chapter 2 describes the Australian policy and demographic context before expanding its focus to report on the review of the literature about care and support work and workers. The methodology and methods for this task are described in Chapter 3. A symbolic interactionist and dramaturgical methodology was chosen and operationalised through the use of ethnographic methods: repeated interviews, observations and the use of photo-voice and photo-elicitation. This chapter also introduces the recruitment approach and the four themes that shaped the data gathering and analysis.

Chapter 4 is the first of four results chapters. Its purpose is to establish the study's context. Thus, it first reports a descriptive review of how care and support work, workers, and clients appeared in local and national newspapers and a national online news source. Additional context is provided by a description of the locale of the study, southern Tasmania. Finally, the twenty-nine participants—and the places in which they live or work—are introduced.

Seventeen of the participants—the care and support workers recruited—are the focus of the second results chapter, Chapter 5. Here, the data on workers’ ‘Presentation of self’, their ‘Performance’ and ‘How workers talked about clients’ is reported. The same three analytic themes are repeated, but focussing on clients, in Chapter 6, before the observed and reported interactions between clients and workers are reported in Chapter 7. This chapter deals with only one theme: ‘Co-constructing meaning’.

Chapter 8, concluding the thesis, maps the themes into a model of relationship and co-creation, based on Axel Honneth’s conceptualisation of the three levels of recognition. Several methodological reflections are then presented, along with discussion of the limitations of the study and implications for provider organisations, before suggestions for further research are offered.

Chapter 2.

The literature

Care: we haven't worked though it yet!

(Hochschild, 2003, p. 7)

Introduction

The focus of this thesis is on how practice and meanings of care intersect in the delivery of support to people with disabilities, whether younger or older. Specifically, my interest is in the experiences of care and support for aged care and disability support workers and their clients. Revealing how care is defined by those engaged in its provision and receipt is thus one of the tasks of the thesis. The literature reviewed in this chapter demonstrates that there is ambivalence surrounding 'care' in ageing and disability, where constructions of care differ. In research and writing on ageing, care tends to be understood as love and altruism, an extension of the self to give ease to another. For disabled people, care is associated with control, institutionalisation, cruelty, and abuse. Despite these differences, the provider organisations, physical practices, and even the individual workers in aged care and disability support frequently overlap. Furthermore, workers and clients from both fields share a sometimes stigmatised position, hidden in backstage settings, engaged in 'dirty' work, and socially and economically marginalised. The voices of workers are rarely heard, and studies that combine empirical foci on meaning and practice uncommon. The service encounter—in residential facility, group house, day centre or private home—is where care and support happen. The actors in these

encounters are meaning-makers; their practices in interactions create and maintain understandings of care. I outline the encounter and the players (Goffman, 1959/1990) before turning to the policy settings that shape encounters and players, and then to how the literature has reported on the work, the workers and the clients, and on the nature of care.

The political environment

Provision of support has been a constant exchange between state and federal governments. Historically, support provision has been shared in varying proportions between state and federal governments and a variety of benevolent and religious societies and charities. Institutional (or residential) 'beds' and pensions and allowances have been a federal responsibility, while states funded most other services and supports.

The first national benefits were aged and 'invalid' pensions (renamed the disability support pension (DSP) as late as 1991), introduced in 1909 and 1910 respectively. The pensions were means tested and funded from general revenue (Herscovitch & Stanton, 2008). Provision of other services to older people and those with disabilities remained the task of state governments and charitable and volunteer organisations. Charities, non-profits and religious organisations continue to have a significant role (Lindsay, 1996).

The return of large numbers of soldiers with disabling injuries from the First and Second World Wars stretched existing support provision and led to the establishment of the Repatriation Commission (1919) and then the Commonwealth Rehabilitation Service (1948), both of which aimed at providing returned soldiers with training to enable their reintegration into the workforce, and to re-establish their place as 'useful' members of society. 'Sheltered workshops' were established. Now known as Australian Disability Enterprises (ADEs), the workshops were intended to provide meaningful employment for

people with severe disabilities. The word ‘sheltered’ referred to their function of sheltering people from having to compete for work on the open jobs market.

Accommodation for people with disabilities provided by both state governments and charitable organisations also increased (Lindsay, 1996).

The impetus that developed after World War II continued with the passing, in 1954, of the *Aged Persons Homes Act 1954*—renamed shortly afterwards the *Aged and Disabled Persons Homes Act 1954*—a bill to regulate the provision of hostel care (McIntosh & Phillips, 2003). As the name implies, nursing homes were imagined as places for people with disabilities as well as the aged. From the mid-1960s, the Commonwealth took greater interest in support for children with disabilities, introducing both a Handicapped Children’s Benefit, provided to children with disabilities living in institutions run by charitable organisations, and the Handicapped Child Allowance, which was intended to encourage parents to support their disabled child at home. These changes shifted the balance of financial responsibility for institutional care away from the states.

By the 1980s, the costs to the federal government of nursing home care, coupled with evidence of inappropriate or unwelcome admissions to nursing homes, shifting public attitudes, and the push for ‘normalisation’ (e.g., see Wiesel & Bigby, 2015) drove several important reforms. The 1983 Commonwealth Government review of programmes for people with disabilities—the first such review in Australia to involve people with disabilities directly—was highly critical of the range of services available, and of the “authoritarianism and paternalism” of providers (Lindsay, 1996, par. 33. Lindsay provides a comprehensive discussion of the development of disability policy in Australia). Recommendations from the review informed the *Disability Services Act 1986* (*Cth*). The *Act* signalled a shift towards community-based support mechanisms—accommodation support, supported employment, training and

placement, for example—for younger people with disability. Meanwhile, aged care was experiencing similar change. The Home and Community Care (HACC) Programme was started in 1985 to provide supports to people with disabilities (regardless of age) in their own homes and in the community. HACC is jointly funded by Commonwealth and State governments. The Commonwealth extended its role in community aged care service provision with the launch of Community Aged Care Packages (CACPs—up to 6 hours support each week) (1992), Extended Aged Care at Home (EACH) and Extended Aged Care at Home Dementia (EACH-D; both up to around 20 hours each week) packages (1998). This was coupled with the formalisation of ‘ageing in place’ policy in the *Commonwealth Aged Care Act 1997*. Similarly, Individual Support Packages (ISP) were created for younger people with disabilities, to provide a tailored range of supports and services to, for example, maintain independence or gain new skills. All reforms were intended to reduce institutional care and support, which were both costly and problematic.

Demographic change and care and support

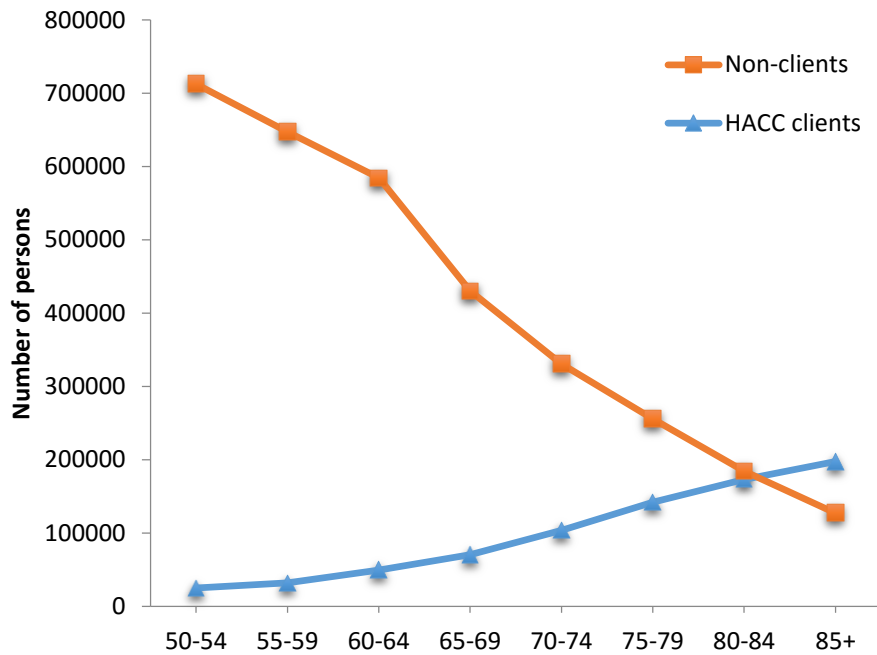
In 2010, the first of the ‘Baby Boomer’ generation turned 65, making them eligible for aged care services. This milestone signals that the proportion of Australians needing assistance with daily living tasks will grow significantly for the medium term (National Centre for Social and Economic Modelling (NATSEM), 2004, p. 26). Models of support provision in which governments play a key role are under pressure both to meet present need and to prepare for future demand.

Demographic changes—like the Baby Boomer milestone—shape the provision of care and support, just as had the return of disabled soldiers. Historically, family members—most often mothers, sisters and daughters—have provided the majority of the care and support needed. The growth in women’s

participation in the workforce¹ over the twentieth century increased the need for waged care and support workers (Held, 2002; Hochschild, 2011, 2012). Further, changes in family structure (lower marriage rates, increased divorce and separation, smaller family size) (Australian Bureau of Statistics, 2007a, 2010b) and the likelihood of people remaining in the workforce longer are predicted to exacerbate the existing shortfall in the number of informal carers (Productivity Commission 2011a, p. 56; NATSEM 2004, p. 30). Nonetheless, family remains the largest source of care and support. It was estimated that in 2009 (Productivity Commission, 2011b) informal carers for people with disability of any age were providing the equivalent of 680,000 full-time (FTE) workers (or more than four times the combined aged care and disability support FTE workforces).

At the same time, life expectancy overall, and the life expectancy of people with disability in particular, has risen. For example, in the 1950s those with Down syndrome might expect to live for 15 years; their life expectancy has now improved to more than 60 years (Productivity Commission 2011c, p. 132). Increased longevity, coupled with a lower birth rate, means that the population is ageing (see Commonwealth of Australia, 2010, p. viii). As the population ages, the proportion of people with impairment increases, such that there is a point at which, as the National Centre for Social and Economic Modelling puts it, “Older age groups contribute more to the disabled population than they do to carer populations” (2004, p. 36) (Figure 2.1).

¹ It remains the case that the majority of informal primary carers (more than two-thirds) for people with a profound or severe core activity restriction are women (Australian Bureau of Statistics, 2009).



Sources: ABS (2010a) Table 7; HACC Annual Bulletin (Australian Department of Health and Ageing, 2011)

Figure 2.1. Number of HACC clients and non-clients, aged 50 and over, 2010–2011

Several recent national inquiries and reports have highlighted the mismatch between people of working (and thus taxable) age, and those who may require support in the form of pensions, health care and so forth (Commonwealth of Australia, 2010; Productivity Commission, 2011a, 2011c, 2013). Internationally, commentary and policy at least since the 1990s (see White, 2004) has tended to regard this phenomenon as a threat; descriptors include ‘tsunami of ageing’, and ‘grey quake’. Although such panic-inducing headlines are increasingly being resisted—in favour of expressions like demographic-, or longevity-, ‘dividend’ (Barusch, 2013; Bloom, Canning, & Sevilla, 2003; Perry, 2009)—all these euphemisms are suggestive of continuing unease about the impaired ‘other’.

In response to these forces, and the inquiries they have generated, aged care and disability support have again been reshaped. The 2012 federal budget included the implementation of a single gateway to access aged care (the

MyAgedCare website), the re-naming and formulation of the Community Care Packages (CACPs, EACH, EACH-D) as Home Care Packages with broader support for people with dementia, and an increase in the number of residential aged care places. Significantly, the change included the introduction of consumer-directed Care packages, intended to give recipients greater control over their support (Commonwealth of Australia, 2012). Most significantly, a major new means of funding support for younger people with disability has been introduced: the National Disability Insurance Scheme (NDIS).²

Support for people with disabilities of all ages has been and remains politically contentious. In the next section some characteristics of this population are given.

The recipients of disability and aged care services

In order to qualify for Commonwealth-funded aged care services, the person must be aged 65 or over, or 50 or over for Indigenous Australians (reflecting their much lower life expectancy). For people younger than that, definitions of disability are applied.

Defining disability

Two key international bodies include the impact of social, cultural and environmental barriers to participation alongside long term incapacity in their definitions of disability. The World Health Organization (2011, p. 4) argues for disability being a social process, rather than “an attribute of the person”.

² The Whitlam government (1972–75) proposed establishing a National Compensation Scheme for Accidents and Sickness in the 1970s, modelled on New Zealand’s system. Legislation was tabled in the federal parliament in 1974; it was not passed. For a legal perspective on both the 2013 and 1974 insurance schemes, see Harrison (2013). Mike Steketee (2013) provides a social sciences perspective and Bonyhandy (2014) and others contribute a span of views in a special issue of *newparadigm* devoted to the NDIS. The enquiry associated with the NDIS was reported in Productivity Commission (2011b, 2011c).

Disability is defined in the 2006 United Nations *Convention on the Rights of Persons with Disabilities* (which was ratified by Australia in 2008), as including “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (United Nations General Assembly, 2006, Article 1).

In Australian policy and statistical documents, the social or environmental dimensions of disability are less explicit. The Australian Bureau of Statistics and the Australian Institute of Health and Welfare define disability as “any limitation, restriction or impairment which restricts everyday activities and has lasted or is likely to last for at least six months” (Australian Bureau of Statistics, 2009, p. 4). They list, for example, loss of sight, shortness of breath or breathing difficulties, chronic pain, seizures, incomplete use of limbs, and the long-term effects of an acquired brain injury. Because of both the desire to constrain support provision costs, and the need to distinguish between varying impacts of limitation, restriction and impairment (at any age), variations in the level of impairment are accounted for by delineating profound from severe limitations to core activity (Productivity Commission, 2011c, p. 95):³

- a profound core activity limitation, where an individual is unable to do, or always needs help with, a core activity; core activities are self-care, mobility and communication, and include washing, toileting, dressing and eating
- a severe core activity limitation, where an individual sometimes needs help with a core activity or task, and/or has difficulty understanding or being understood by family or friends and/or

³ People may also experience ‘moderate’ or ‘mild’ limitations.

can communicate more easily using sign language or other non-spoken forms of communication.

The ‘client’ participants in this study are people who experience profound or severe limitations to core activity.

Demography of disability

According to the Australian definition, there were 4.2 million Australians of any age with a disability in 2012, and 1.4 million of them had a profound or severe limitation to core activity (6.1% of the population) (Australian Bureau of Statistics, 2013a). Disability increases with age, so that almost three-quarters of Australians aged 85 report living with disability. Disability is more commonly experienced by women than men—of people aged 75 and over, 40 per cent of women and 26 per cent of men have a profound or severe core activity limitation (Australian Bureau of Statistics, 2013a).

This age-related effect is important when considering the Tasmanian situation. At the last national census (2011) nearly 17 per cent of all Tasmanians were aged 65 or more; nationally the figure was 14 per cent. Of these older Tasmanians, almost 21 per cent had a profound or severe core activity limitation. For younger Tasmanians, too, rates of profound or severe disability are higher than the national average: 4.77 per cent report a disability (Australian Bureau of Statistics, 2013a), compared with 3.7 per cent nationally. That is, 7.5 per cent of Tasmanians and 6.1 per cent of Australians overall report having a profound or severe core activity limitation.

Socio-economic conditions

Overall, 87 per cent of people with disability live in a private household. About 20 per cent of people with profound core activity limitations and 3 per cent of people with a severe limitation live in “cared accommodation” —including

hospitals, aged care or disability residential facilities, group houses or other supported accommodation (Australian Bureau of Statistics, 2013a).

“Cared accommodation” is not always suitable for the residents’ needs. Some younger people with disabilities live in aged care facilities. Similarly, residential facilities for people with disabilities are frequently home for people who are ‘ageing in place’. At June 2011, there were 6,381 Australians aged under 65 living in residential aged care facilities, and 658 of them were aged less than 50 (Australian Institute of Health and Welfare, 2012, p. 6). In Tasmania, in 2010, there were 161 people aged under 65 living in aged care facilities (Productivity Commission, 2011c, p. 118).

These statistics about living conditions provide only an outline; they do not convey the real conditions of people’s lives. People with disabilities and their carers “are among the most disadvantaged groups in Australian society. This can be seen through measures of social isolation, financial status, as well as personal wellbeing” (*Productivity Commission, 2011c, p. 111*).⁴ Families may be unable or unwilling to provide appropriate support. Poor employment opportunities also contributes to social isolation and to low income; only about one third of people of working age with disabilities has paid employment (Productivity Commission, 2011c). The question of employment for people with disability remains vexed (Bourke, 2014; McDermott & Edwards, 2012; Soldatic & Chapman, 2010).

Needs and supports

More than half (57%) of disability service users need assistance with work, education and community living, and a similar proportion (52%) needs some

⁴ ACOSS (2014, p. 27) reported that “The poverty risk among DSP recipients was [...] 48%. This is due to the fact that DSP is income and assets-tested so that many of the ‘poorest’ people with disabilities receive that payment”. They also note that their data does not take into account the greater costs of living for people with disability.

assistance with activities of daily living (ADLs);⁵ even more (61%) need assistance with independent living (Australian Institute of Health and Welfare, 2013b). Some of these needs are for repeated help in a single day. For example, more than one in five people with disabilities needs help more than six times a day for a core activity; a similar number needs help between three and five times a day (Productivity Commission, 2011c, p. 97).

Across Australia, a large number of people use disability and aged care services and supports. Table 2.1 presents the numbers of recipients of government support, and which programs they were being supported by in 2012 (prior to the introduction of the NDIS and new Home Care Packages).

Table 2.1. Recipients of care or support, 2011–12

Program	Users	Subtotals
Residential aged care		167,009
—low care	45,093	
—high care	121,916	
Home care packages		53,975
—CACF	42,835	
—EACH	7,757	
—EACH–D	3,383	
HACC services		957,448
—older users	746,859	
—younger users	207,315	
Disability services	317,616	317,616
	1,492,774	1,496,048*

* Total is larger as it includes HACC users whose aged was not known.

Sources: Aged Care Financing Authority (2013); AIHW (2013a)

⁵ According to the OECD (2007): “One of the most common categorisations of dependency, but not the only one, is the degree of difficulty performing activities of daily living (ADLs) and instrumental activities of daily living (IADLs). The degree of difficulty people experience in carrying out ADLs and IADLs denotes their level of dependency. ADLs is a core set of self-care or personal care activities which includes bathing and washing, dressing, feeding, getting in and out of bed, getting to and from the toilet and continence management. In the above definition of disability, ADL restrictions are activity limitations which imply that an individual has difficulty in executing daily activities. IADLs relate to domestic tasks such as shopping, laundry, vacuuming, cooking a main meal and handling personal affairs. IADL restrictions may otherwise be considered as participation restrictions or problems an individual may experience in involvement in life situations. Assistance with ADL denotes a higher degree of dependency than assistance with IADLs and thus is associated with more intensive care” (p. 2).

While it is not common for people to receive support from more than one program, it is possible; therefore, the total number of recipients is an approximate figure.

For people using disability-specific services, an indication of assistance needed may be derived from data on the limitations affecting disability service users in Tasmania and nationally (Table 2.2).

Table 2.2. Characteristics of disability service users, 2011–12

Primary disability group	Users—Tasmania	—Australia
Intellectual	1,924	85,550
Specific learning/ADD	481	13,709
Developmental delay	553	10,391
Autism	392	18,639
Physical	1,464	50,682
Acquired brain injury	435	10,989
Neurological	453	18,060
Deaf-blind	4	999
Vision	23	13,928
Hearing	33	11,658
Speech	539	3,843
Psychiatric	50	56,733
Not stated	4	20,368
Not collected (recreation/holiday programs)	108	2,067
Total	6,463	317,616

Source: Australian Institute of Health and Welfare (2013a)

Such intensive assistance requires either the presence of a willing and capable informal carer, or the well-planned provision of assistance via support workers. The nature of the assistance ‘products’ are described in the next section, then the workers delivering services and supports are introduced.

The nature of care and support work

People with disability—whatever their age—may need assistance with their everyday tasks. In Australia, such assistance may come via one of a variety of

programs and packages (Home Care, Home and Community Care (HACC), Individual Support Package (ISP), for example) and providers. They may be delivered in private houses, supported accommodation or residential facilities, or another setting. The sorts of tasks performed by the workers in this study are encapsulated satisfactorily by five HACC assistance categories: domestic assistance, personal care, social support, meal services and transport. For all these assistance categories, the Australian Bureau of Statistics (2013a) reports that a gap exists between need and provision; even where support is delivered, it may not fully meet the need. Data in this section are drawn from the most recent national census.

Domestic assistance helps people with household tasks like cleaning, dishwashing, clothes washing and ironing, and unaccompanied shopping. Care and support workers in residential facilities are rarely expected to do these tasks, while in the community, they make up a large part of the work. Almost half of all HACC recipients received domestic assistance in 2010–11.

Conversely, supporting people with their personal hygiene and grooming (personal care) is a significant activity in facilities, and much less common in the community (around 13% of Tasmanian HACC clients; Australian Government Department of Health and Ageing, 2012). Support of this kind may be for eating, bathing, using the toilet, dressing, grooming, getting in and out of bed, and moving about the home. Nationally, more than half a million received personal care support (Australian Bureau of Statistics, 2013a). About 300,000 people received meal preparation support in 2012 XX. In residential facilities, there are usually cooks (or food is brought in from hospitals, for example). There, care and support workers may sometimes prepare a weekend meal, but assistance with preparing and cooking is fairly common in the community. Here, support may also include advice on nutrition, storage and food

preparation. Three-hundred thousand people reported a need for assistance with meal preparation in 2012 (Australian Bureau of Statistics, 2013a).

Social support and transport both assist clients to participate directly in community life. Workers—using their own or company cars—may drive clients to work, to medical and other appointments, take them shopping or to social engagements. Or workers may simply visit. Social support was provided to about 14 per cent of HACC clients in 2010-11 (Australian Government Department of Health and Ageing, 2012), and transport assistance was provided to 593,400 people.

The workers who deliver ‘hands-on’ care and support

The five broad categories of support described in the previous section, intended to enable recipients to engage more fully with the tasks and activities of daily life, are overwhelmingly delivered by care and support workers (defined as ‘community and personal service workers’) in the health and social care workforce. In 2011, the health and social care workforce was the largest sector in the Australian economy, at 11.6 per cent of the total (Australian Bureau of Statistics, 2011, 2012a). People employed in the sector include managers, professionals—medical specialists and other practitioners, registered and enrolled nurses, and allied health professionals—technicians, clerical and administrative workers, salespeople and machinery operators and labourers. An additional 30 per cent of this workforce are community and personal service workers (making them 3.5 per cent of the entire national workforce) (Australian Bureau of Statistics, 2012a). In Tasmania, the health care and social assistance sector makes up almost 12 per cent of the Tasmanian workforce, with more than a third of them being community and personal service workers (4.5% of the total Tasmanian workforce) (Australian Bureau of Statistics, 2012a). Tasmania

had 9, 723 community and personal services workers in the health and social care workforce in 2011.

In aged care facilities, these workers are generally known as personal care assistants (PCAs). In the community, they may be called community care workers (CCWs) or support workers. Those specifically delivering services to younger people with disabilities are usually known as disability support workers (DSWs).

Pay and conditions

Care and support workers are among the lowest paid in Australia. In 2012, when the national average wage was \$1080.30 per week (Australian Bureau of Statistics, 2012c),⁶ community and personal service workers were paid an average of \$707 (total cash earnings) a week (Australian Bureau of Statistics, 2013b). In aged care, the median weekly wage for PCAs was \$653; for the more than half of all PCAs who worked between 16 and 34 hours a week, it was \$600 (D. King et al., 2012a). For CCWs, the gross median weekly income was lower: \$600.

Care and support work is characterised by high levels of part-time work (D. King et al., 2012a), and fairly high staff turnover (Howe et al., 2012; D. King, Wei, & Howe, 2013). The majority of PCAs, CCWs and DSWs are employed on a permanent part-time basis, with workers in the community and DSWs more likely to be working on a casual or contract basis (see Table 2.1). Many PCAs and CCWs work between 1 and 15 hours a week; for these workers, the median weekly income was \$269 (King et al., 2012). For DSWs, Martin and Healy (2010) report that, in 2009, “about one quarter [of the disability support workforce] had very low gross earnings of less than \$400 per week. Moreover, three quarters earned less than a modest \$800 per week” (p. 119). About one third

⁶ This is the average weekly wage for all workers, whether full-time, part-time or casual.

received less than \$20 per hour, and a further 38% received between \$20 and \$24 per hour (Martin & Healy, 2010).

In June 2012, an Equal Remuneration Order was made by Fair Work Australia (now the Fair Work Commission) to increase pay rates for workers covered by the Social, Community, Home Care and Disability Services Award 2010 (the SACS award) (Charlesworth & Macdonald, 2015; Cortis & Meagher, 2012). SACS applies to some workers in the health care and social assistance sector, including those in disability services, and those working in residential settings, respite centres and day services. The pay increase did not apply to workers providing in-home domestic assistance to an aged person or a person with a disability. Whether in receipt of this increase or not, workers remain quite low paid (and see Chapter 4). As Masterman-Smith and Pocock (2008) suggest, pressures on the low paid (of simply managing daily demands) restrict them from engagement with employers and unions; they are “shut out of the conversation” (p. 222).

Workers in the health and community services sector report relatively high injury rates, as well as work-related illnesses. Work-related injury or illness was reported to King, Macvromaras, Wei, He, Healy, Macaitis, Moskos and Smith (2012) by 15 per cent of residential aged care workers (for the preceding year). In the community sector, 12 per cent of workers reported a work related injury or illness (D. King et al., 2012a, p. 102). The work-related injury rate for both male and female health and community services workers was high. Ninety-six men in a thousand employed in the sector reported an injury in 2007, making this the fifth most prevalent site of work-related injury for men. For women, the injury rate is lower (at 71 per 1,000), but this is the sector with the second highest injury rate for women in Australia, after accommodation, cafes and restaurants (Australian Bureau of Statistics, 2007b). King et al. (2012a, pp. 160-161) reported that the most common injuries related to the work’s physical

demands (lifting, pushing, bending and so forth), which resulted in sprains, muscle and joint pain, and strains. Further, workers risk injuries caused by the people they work with, including being hit or bitten.

Similar health and safety risks have been reported by Markkanen, Quinn, Galligan et al. (2014); workers in their qualitative study reported both musculoskeletal injuries and disorders as well as being verbally abused by clients. Verbal and physical abuse from clients (and, in community settings, client's family members) are not uncommon. Of the more than 1,000 home care workers interviewed in Geiger-Brown, Muntaner, McPhaul, Lipscomb and Trinkoff's (2007) study, nearly 5 per cent reported experiencing physical violence and 18 per cent had experienced verbal abuse.

Workers' idealism sometimes means that they accept unsuitable or dangerous conditions and risks posed by clients (Kosny, 2006). Support work is "tailor made for putting the needs of other before one's own" (Gass, 2004, p. 74). Such meekness may in part explain the under-reporting of incidents of violence and abuse of care and support workers found by Goodridge, Johnston and Thomson (1996). Gass's (2004) ethnographic study of working in an American nursing home includes several examples of his own vulnerability, including interactions with 'Zelda' in which he feels "Degraded as the instrument that makes her world order much tidier than my own will ever be" (p. 155). Kosny and Maceachen (2010) reported on the emotional demands that sit alongside the risks of violence and stress, arguing that these 'hazards' often remain invisible. Stress or other mental conditions were reported to King et al. (2012) by 20 per cent of community and 13 per cent of residential facilities.

Worker demographics

The most comprehensive Australian information available about workers in aged care and in disability services comes from several studies conducted by

the National Institute of Labour Studies (NILS) (e.g., Healy & Moskos, 2009; D. King et al., 2012a; Martin & Healy, 2010; Martin & King, 2008; Richardson & Martin, 2004). Richardson and Martin (2004) gathered statistics on direct care workers (personal care workers, as well as nursing and allied health staff) in residential aged care settings, and subsequent NILS studies have expanded to include aged care workers in community sectors (D. King et al., 2012a; Martin & King, 2008). In 2010, Martin and Healy reported on *Who Works in Community Services*, providing data on the disability (as well as child protection, juvenile justice and general community services sectors) workforce. Worker numbers are given in Tables 2.3 and 2.4.

Table 2.3. Aged care workforce data, 2012

Support Work Role	Sector	Total workers (and as a percentage of the direct care workforce)	FTE
PCA	Residential aged care	100,312 (68.2%)	64,668 (68.2%)
CCW	Community support/aged care	76,046 (81.4%)	41,394 (75.9%)

Source: King et al. (2012a)

Table 2.4. Disability support workforce data, 2009

Support Work Role	Sector	Total workers (and as a percentage of the total disability services workforce)	FTE
DSW (CCWs, PCs, HCWs, D&RSW)	Disability	42,594 (62%)	25,000

Source: Martin and Healy (2010)

These reports provide a picture of the workers in aged care and disability. The profiles are very similar. Both sectors are dominated by women (Moskos, 2012, discusses occupational sex segregation), and workers in both sectors are most likely to be employed on a permanent part-time basis (Martin & Healy, 2010; Martin & King, 2008). Since Richardson and Martin's (2004) report, the average age of workers has increased, as has the proportion with a Certificate level

qualification (D. King et al., 2012a).⁷ Demographic information for these workers is given in Table 2.5 below.

Table 2.5. Demographic data on care and support workers

	Median age	Median age of new entries	Gender (direct care worker)	Qualified: Cert III in relevant field	Percentage who are permanent part-time employees	Percentage who are casual or contract employees
RACFs (PCAs)	47	38	89% female	73.4% 20% (Cert IV)	73.6	19.5
Community (CCWs)	50	45	90% female	68% 13.3 (Cert IV)	62.9	30.4
Disability (DSWs)	40–49	n/a	80%* female	54% (Cert III or IV)	55	31

*In Tasmania, the proportion of men in the disability services workforce is higher, at 24%.

Sources: Aged care workforce data is from King et al. (2012); disability services workforce data is from Martin and Healy (2010)

What studies have focused on these workers?

The foregoing shows that there has been demographic attention paid to aged care and disability support workers. These workers are the least formally qualified in the broader health sector workforce and, reflecting the hierarchical nature of the sector (Elwér, Aléx, & Hammarström, 2010; England, Budig, & Folbre, 2002; Fine, 2007b), have tended to be overlooked in research focused on aged care and disability support. There has been interest in nurses and other professionals in aged care (the people sometimes referred to as the ‘trained staff’) where studies have looked at their attitudes, experiences of recipients and settings, turnover, work patterns, sense of self-efficacy, training, and skills (including Blomqvist, 2003; Boström, Kajermo, Nordström, & Wallin, 2009; Brand & McMurray, 2009; Brodaty, Draper, & Low, 2003; Duffy, Oyeboode, &

⁷ “Vocational education and training (VET) ... qualifications are outcome-based and focus on the occupational skills and competencies gained. ... Qualifications range across four levels of certificates (Certificate I, II, III and IV), as well as Diploma courses and Advanced Diploma courses” < <http://www.studyinaustralia.gov.au/global/australian-education/vocational-education/vocational-education-qualifications>>.

Allen, 2009; Evers, Ploeg, & Kaasalainen, 2011; Fine, 2007a; Henderson, Xiao, Siegloff, Kelton, & Paterson, 2008; Howe et al., 2012; Jansen & Morse, 2004; Lookinland & Anson, 1995; Lovell, 2006; Norbergh, Helin, Dahl, Hellzén, & Asplund, 2006; Phillips, Salamonson, & Davidson, 2011; Skovdahl, Kihlgren, & Kihlgren, 2003).

Studies of care or support workers are most likely to be reported in studies of organisations and workforce. For example, several studies have considered the factors that affect these workers' job satisfaction and intention to stay in the role (e.g., Ahlström & Wadensten, 2012; Banaszak-Holl & Hines, 1996; Coogle, Head, & Parham, 2006; Fleming & Taylor, 2007; Gilster & Dalessandro, 2008; Howe et al., 2012; Kuo, Yin, & Li, 2008; Larson, Hewitt, & Anderson, 1999; Martin, 2007; Rakovski & Price-Glynn, 2010; Shinan-Altman & Cohen, 2009; Stajkovic & Luthans, 1998; R. Stone, Dawson, & Harahan, 2004; Vassos & Nankervis, 2012; Vernooij-Dassen et al., 2009; Zimmerman et al., 2016; Zimmerman et al., 2005), as well as the relationship between worker efficacy and quality of care (e.g., Bishop, 2008; Caspar & O'Rourke, 2008; Cohen-Mansfield & Werner, 1995; Coogle, Jablonski, Rachel, & Parham, 2008; Skovdahl et al., 2003; Sormunen, Topo, Eloniemi-Sulkava, Raikkonen, & Sarvimaki, 2007). Bill Martin and Debra King (2008) (and see D. King, 2012; D. King & Martin, 2009) also identify themes of commitment to recipients, and the role of emotion in the work as a source of both burden and satisfaction.

In disability support, attention has been similarly narrow. For example, there has been a focus on burnout (Alamri et al., 2011; Devereux, Hastings, Noone, Firth, & Totsika, 2009; Hatton et al., 1999; Mills & Rose, 2011; Mitchell & Hastings, 2001; Shaddock, Hill, & van Limbeek, 1998; Skirrow & Hatton, 2007; Webber, Bowers, & Bigby, 2016), attitudes of workers to those they assist (Aylott, 1999; Bazzo, Nota, Sores, Ferran, & Minnes, 2007; Cuskelly & Bryde, 2004; Gilmore & Chambers, 2010; Hamilton, 2009; Murray & Minnes, 1994;

Szollos & McCabe, 1995), and demographics, training and skills (Community Services & Health Industry Skills Council, 2014; Healy & Moskos, 2009; Jørgensen et al., 2009; Martin & Healy, 2010).

As well, informal caregivers—family members or friends who provide care and support for frail aged people or people with disability—are prominent, particularly their experiences of caring in terms of physical and emotional work (for example, Beckett, 2007; Burton-Smith, McVilly, Yazbeck, Parmenter, & Tsutsui, 2009; Carretero, Garcés, Ródenas, & Sanjosé, 2009; Etters, Goodall, & Harrison, 2008; Garcés, Carretero, Ródenas, & Sanjosé, 2009; Janicki, Zendell, & DeHaven, 2010; McConaghy & Caltabiano, 2005; Pinquart & Sorensen, 2003, 2006; Rosa et al., 2010; Shakespeare, 2006; Sims-Gould & Martin-Matthews, 2010; Spitznagel, Tremont, Davis, & Foster, 2006; Stull, Kosloski, & Kercher, 1994). A prevalent theme in studies of informal caregiving for older people is that of ‘carer burden’. At the same time, there is only a fairly small literature on the experience of frail older people receiving care either from family or from organisations. Their voices are largely absent from studies dominated by informal caregivers or professional staff. In contrast, in disability studies, several of the key researchers are disabled people or people who directly support a family member with disability (e.g., Jenny Morris, Tom Shakespeare, Eva Feder Kittay). Perhaps reflecting different levels of agency⁸—and certainly different levels of activism—the notion of (informal) carer burden is commonly questioned in disability studies and taken-for-granted in aged care writing.

Studies focused on workers delivering care and support have considered the impact of marketised models, relationships and emotion, protection and

⁸ Peter Berger’s way of describing agency seems apt. He writes that, unlike marionettes, manoeuvred by a puppet master, “we have the possibility of stopping in our movements, looking up and perceiving the machinery by which we have been moved” (1963, p. 199). This “first step towards freedom” means we can—at least to some extent, or in some circumstances—take over the controls.

independence, power and inequality, person-centred or ‘humanized’ (Lopez, 2014) models, risk, reward and sources of meaning for workers. Several of these studies have used ethnographic methods, with researchers being (at least temporarily) ‘insiders’, or using interviews and observations to gain rich information (Buch, 2013, 2015; Christensen, 2005-2006, 2009, 2010, 2012; Christensen, Guldvik, & Larsson, 2014; Fjær & Vabø, 2013; Gass, 2004; Greener, 2011; Guldvik, Christensen, & Larsson, 2014; Hawkins, Redley, & Holland, 2011; Lopez, 2006, 2014; Sidenvall, 1999; Sidenvall, Fjellström, & Ek, 1996a, 1996b; Sims-Gould & Martin-Matthews, 2010; Stacey, 2005; Wolton, 2013).

Examinations of the intersection of markets and paid care and support tend to support Christensen’s conclusion, that “[n]o cash for care system will ever be able to fundamentally resolve the basic contradiction between the independent living perspective and the careworker perspective” (2010, p. 251). Cash-for-care arrangements provide little opportunity for workers to practice or experience co-determination (Guldvik et al., 2014). When disabled people are direct employers of support workers or assistants, professional, ‘solidarity/emotional’,⁹ or master-slave relationships may result (Christensen, 2012). Such “strongly hierarchical or strongly emotional relationships” are probable “if this relationship is self-regulated or regulated by a third party (whether profit or non-profit party) working only for one side of the cash-for-care relationship, usually up to now, the disabled person” (Christensen, 2012, p. 409). Christensen proposes that an active third party, attentive to the interests of both people, be involved. Woodin (2006) also considered third parties. She explored how paid assistants mediate disabled employers’ social relationships

⁹ Solidarity, here, refers to a sense of individual emotional connection, rather than the solidarity of being part of a larger project, and contributing something “of constitutive value to a concrete community” (Honneth, 1997, p. 30).

including at home or in workplaces, and reported that existing household or family structure was influential.

Three studies of care and support workers and work encapsulate many of the overarching experiences and tensions. These are the work of Christensen, Guldvik and Larsson (2005-2006, 2009, 2010, 2012; 2014) discussed above, Stacey's (2005) study of home care aides, and the Canadian Institutes of Health Research project, "Home Care in Canada: Working at the Nexus of the Public and Private Spheres" (Byrne, Frazee, Sims-Gould, & Martin-Matthews, 2013; Cloutier, Martin-Matthews, Byrne, & Wolse, 2015; Sims-Gould, Byrne, Beck, & Martin-Matthews, 2013; Sims-Gould, Byrne, Craven, Martin-Matthews, & Keefe, 2010; Sims-Gould & Martin-Matthews, 2010).

Stacey conducted a study focused on how workers "assign meaning to their 'dirty work'" (p. 832). Community-based workers in her study experienced overwork, risk and physical and emotional strain, alongside autonomy, skill-building and the rewards of mastering 'dirty work'. Meaning in Stacey's study was reported to reside in the work, rather than being created in relationships. Clients' role in this meaning-making was seen only from the workers' perspective. Further, clients' marginalisation was compounded by Stacey interviewing some workers while they worked, a practice she supported by stating that "in most cases the client was asleep in another room or did not appear sufficiently mentally competent (or interested enough) to follow the conversation" (Stacey, 2005, p. 835). Clients' presence may have mediated workers' responses and, more importantly, Stacey did not address the question of what the othering of the recipient meant for the workers, for the clients, or for the study as a whole. This denial of the other is added to by the problem of workers, while being paid to work, in fact doing something else.

The "Home Care in Canada" study was a large mixed methods exploration of workers', clients' and family-caregivers' experiences of in-home support. Where

family caregivers' data was discussed (Sims-Gould & Martin-Matthews, 2010), direct care and assistive care were identified as overarching themes, and these were then further broken into instrumental (that is, caring *for*) and affective (caring *about*) aspects of workers' help. When workers in the study were interviewed about recruitment and retention (Sims-Gould et al., 2010), the relational aspect of the work was found to be a "major attractor" (p. 186). Cloutier (2015) described the significance of clients' home in shaping the support experience for aged care workers and clients. Finally, Byrne et al. (2013) found that clients wanted support interactions that preserved their autonomy, and supported personhood. Considering the overarching study, the authors note some important limitations. Firstly, they could not match the family caregiver, client and worker samples, and therefore did not find out about the characteristics of the particular workers associated with the informal caregivers and clients. This led them to propose that: "Research that examines the responses from dyads or triads of workers, clients and/or family members would enhance our understanding of the interactive nature of home support" (Sims-Gould et al., 2010, p. 422). Secondly, Byrne et al. suggest the need for an observational research design to "shed light on the nature of the interactions between workers and clients" (p. 395).

All these studies have reported that workers can have "limited agency or prestige" (Kelly, 2011, p. 566). This is especially so in arrangements where the worker has to respond to the employer "without complaint" (p. 566). Versions of this subordination were reported by Buch (2010; 2013), Kelly (2011), Gass (2004), Greener (2011), Lopez (2006, 2014), and Guldvik (2014). Buch, for example, noted the significant effort workers made to ensure that clients' ways of living were maintained. Often, such continuity was facilitated by workers accepting marginal social positions and relative invisibility. Care work could readily reproduce structural inequalities. These studies also highlight the

coercive aspect of care and the inherent tension where care appears to involve domination and submission, in either direction. This has been flagged by Fine (2007a) as the 'dark side of care'. Almost celebrating these complexities, Kelly (2011), argues that we need to keep the concept of care:

at hand to help to highlight the best and worst potential of personal assistance. Care can be made accessible by continuing to work on it and grapple with it. Care as an ambiguous, contested and complex term is roomier than 'attendant services' and helps expand the definitions of what personal assistance, and disability are. This can be done carefully, cautiously and critically with frequent pauses to reflect on the legacies and debates around the concept. (p. 578)

How care has been theorised about is the subject of the last part of this chapter.

How care is discussed in the literature

The relative absence of workers' experiences of the practice and meaning of care reflects what Michael Fine (2007b) calls the social division of care.¹⁰ He discussed care provision hierarchies, arguing that the medical profession maintains a "monopoly over curing" (Fine, 2007b, p. 142), while nursing has continued to take ownership of caring. Further, as Fine notes (citing Leninger, 1988, and Benner, 1984, 1994), nursing theorists have increasingly emphasised the communications aspects of caring rather than the 'hands-on' as:

crucial for the legitimisation of the emergent hierarchical division of labour in nursing, where smaller numbers of tertiary educated registered nurses are increasingly responsible for supervisory and managerial tasks, while less costly, less qualified care workers and assistants assume an increasing proportion of the responsibilities. (Fine 2007b, p. 142)

The relative absence of registered nurses and other clinicians from day-to-day care settings (aged care, disability support) means that nursing's ownership of care relies on definitions which approximate care *about* rather than care *for*, a distinction identified by Waerness (1984, 2004). The low status, 'dirty work' — the caring *for* — is left to the "less qualified junior staff" (Fine, 2007b, p. 142).

Several important points arise from Fine's setting out of the ways in which care is discussed in the literature. First, there is a continuing lack of agreement about what the term means; thus he argues that care cannot be used as "a reliable social measure in its own right" (Fine, 2007b, p. 143). Second, Fine cites Graham (1983, 1991) in noting that what is understood by the word 'care' is in flux (Fine & Glendinning, 2005); it comprises "intangible affective/cognitive elements" (caring *about*) and "observable, material actions" (caring *for*) (Fine, 2007b, p.

¹⁰ Fine writes that: "The concept of social division of care is based on the recognition of care as a form of work, rather than on the institutions through which it is provided or the financial resources which makes this possible. ... The concept of the social division of care is intended to direct the focus of attention ... towards the way that care is organised as a form of work, and as a social relationship between recipient and provide[r]" (2007b, p. 146).

143) (this is congruent with the themes discussed by Sims-Gould & Martin-Matthews, 2010, and Christensen, 2009). A definition, then, might encompass three related ideas:

1. Care as a disposition (though this is somewhat countered by the work of D. King, 2007; D. King, 2012, who found that a disposition to care is not essential for the effectiveness of workers).
2. Care as a form of work (a physical task demanding competence).
3. Care as a “*social and personal relationship*” (Fine 2007b, p. 144) (emphasis in original) with an element of support (and see Featherstone, 2010).

This third element is explored by Isaksen (2002, p. 793) who cites Wærness’s work on care to describe caring as encompassing “that range of human experiences that has to do with feeling concern and taking charge of the well-being of others. This is a definition that tells us that caring is both social activities and emotions”. Lappalainen and Motevasel (1997, p. 191) also apply Wærness’s (2004, 1984) conceptualisation to define care as an activity in which “relations of trust are created and, through listening and sympathy as well as practical work, they contribute to the well-being of the other”. This implies an emergent and relational meaning.

The social division and construction of care includes a sexual division. King et al. (2012a) report that in 2012, 89 per cent of care and support workers in Australian aged care facilities were women. This is a decrease on the figure of 93 percent 2007. In the community, there has been less change—the proportion of women has dropped from 91 per cent to 90 per cent. In disability support there is a somewhat higher proportion of men, but in 2009, 80 per cent of the ‘non-professional’ workers in disability support were women (Martin & Healy, 2010). While there has been a small shift, Held’s (2002) summary still stands: many of the paid roles dominated by women are “ill-paid version[s] of the unpaid caring work they do at home” (p. 21). The low wage can aptly be called a “care penalty” (England et al., 2002). This penalty is experienced by those

with caring jobs: teachers, careworkers, nurses, as well as doctors and university professors who are "... willing to accept this penalty because they feel that the rewards of their work extend beyond wages and benefits. Instead, being a good caregiver is central to their own sense of self" (Macdonald & Merrill, 2008, p. 129), echoing ideas of care as a disposition. MacDonald and Merrill (2008) argue, additionally, that people in care roles experience:

... a failure on the part of their employers (and sometimes the recipient of their care) to grant recognition to the work that is rooted in their self-conception. Many of the soft skills performed by caregivers are simply assumed to be a natural part of their ethnic heritage or the fact that they are a woman. (p. 129)

Further, neo-liberalism has embraced such ascription of 'soft skills' and the responsibility for care to women (see Lappalainen & Motevasel, 1997), proposing that "the basis for this work should be "the breadth of love—not the narrowness of money" (Ungerson 1995: 45)" (Lappalainen & Motevasel, 1997, p. 194). The matter of what activities should be marketised, and the impact of marketisation on an activity has been taken up by Held (2002) who echoes the neo-liberal notion that "exchange or market value is one of the least appropriate ways in which to think of its value" (p. 22).

Hochschild has written extensively (1995, 2003a, 2003b, 2011, 2012) about the "outsourcing" of care and emotion. Her sociology traces the progressive commodification of acts that were hitherto performed out of love/an expectation or duty, or for the beneficial social exchange they imply. Lawson (2007) argues that the increasing privatization this reflects has "sobering implications for social justice and gender division of labor" (p. 2). New forms and locations of inequality result, including what Hochschild (2001, par. 3; Raghuram, 2012) calls the "global care chain" in which workers from low-pay areas travel to better pay areas to work in service roles, leaving a care gap at home to be filled by a yet lower waged worker. The burden of care remains on people who are women, in ethnic minorities and/or immigrants. In the process,

care work continues to be “systematically devalued as the feminized, private work of home, rather than as society’s work” (Lawson, 2007, p. 2) (and see Lappalainen & Motevasel, 1997). This disables the workers from both providing care and from receiving care when they need it, effectively marginalizing care and rendering it invisible (Lawson, 2007).

The gendering of care and support and the concomitant penalties have fed an evolution in thinking on care. Gilligan’s (1982) response to work on the moral development of adolescents was seminal. She concluded (on the basis of a series of experiments on male and female adolescent moral development conducted by Kohlberg¹¹) that:

sensitivity to the needs of others and the assumptions of responsibility for taking care lead women to attend to voices other than their own and to include in their judgment other points of view. Women’s moral weakness, ... is thus inseparable from women’s moral strength, an overriding concern with relationships and responsibilities. (Gilligan, 1982, pp. 16-17)

Thus, some feminists proposed an ethic of care (Gilligan, 1982) that “revolves around relationships and responsibilities, in contrast to an ethic of justice which stresses rights and rules” (Featherstone, 2010, p. 74). It posits “the image of a “relational self”, a moral agent who is embedded in concrete relationships with others and who acquires a moral identity through interactive patterns of behaviour, perceptions and interpretations” (Parton, 2003, p. 10; cited in Featherstone, 2010, p. 83). This emergent moral identity and meaning may be important for workers. Some feminist scholars embraced the ethic of care model because it valorises care as a site for what are proposed as femininities—intimacy and reciprocity—which “cannot find expression in a society dominated by the male imaginary” (Hughes, McKie, Hopkins, & Watson, 2005,

¹¹ In the experiments, the boy used a system of logic and law to respond to a hypothetical ethical dilemma, while the girl focused on relationships; he therefore ranked higher on Kohlberg’s scale of moral development.

p. 260). Gilligan's work "signalled a shift away from the emphasis in second-wave feminism on equating care with oppression and exploitation" (F. Williams, 2001, pp. 75-76), an ongoing consideration in the disability literature. But valorising these so-called femininities has not increased their social and economic prestige. Critics have argued that an ethic of care approach 'essentialises' women (that is, fails "to deconstruct the category of woman" (Featherstone, 2010, p. 75)) as naturally care-oriented, nurturing and relationship-focused and continues the naturalisation of care to women (and see Skeggs, 2008 on feminism in sociology). The invisibility of the carer is valued (Clifford, 2012). As well, Lappalainen and Motevasel (1997) report that later tests of Gilligan's work found that "only women with little education and women outside the labour market possessed a "feminine" ethic of care" (p. 190), suggesting that economic imperatives deserve more credit. Lappalainen and Motevasel (1997, p. 194) further countered that the "intrinsically feminine" ethic of care model can be a burden to women working in situations that preclude relationship-centred care and may lead to women being "expected to take increased responsibility for elderly and handicapped people, and perhaps also engage in "voluntary social work" and charity" (Lappalainen & Motevasel 1997, p. 194). As well, the ethic of care model may either excuse men from relationship and care responsibilities, position male care and support workers as feminine, or render them invisible, their capacity to support and nurture disregarded. Finally, Williams (2001) criticised Gilligan for assuming that care was located in the heterosexual family, and for ignoring the "set of relations involving power and featuring both carers and cared-for" (F. Williams, 2001, p. 476).

Power, dependence, independence, interdependence

Care, then, is a site of a complex 'set of relations'. The presence of power in care is taken up in debates around dependence, independence and interdependence

(Fine & Glendinning, 2005). In the care dichotomy involving a young, 'able', active person and an old or disabled, 'dependent', passive 'non-actor', to "be cared for is to be in deficit and to have one's competence as a social actor denied or questioned" (Hughes et al., 2005). The dependent person is "constructed as the general and totalized other" (Weicht, 2011, p. 209)—a view that echoes Morris (1997, 2001).

Much of the discussion around dependence and independence has come from disability research (e.g., Christensen, 2005-2006, 2009, 2010; Helgøy, Ravneberg, & Solvang, 2003; Hughes et al., 2005; McArthur, 2012; Shakespeare, 2006; Young, 2011). In the clash between duty of care and independence (or autonomy), "what attendants consider the 'best interest' of the disabled people they serve [sic] may not align with the opinions of the disabled people themselves" (Schelly, 2008, p. 572). It can be unclear when "'cueing' [or prompting] and 'supervision' are appropriate and when they are oppressive or controlling" (p. 572). Hawkins et al. (2011) described workers in residential facilities managing this conflict by trying to have independence-promoting elements incorporated into care plans and by taking professional risks. They "allowed residents to do small tasks unsupported out of sight of colleagues, but were held accountable for their actions if discovered" (p. 881). One response is to define the support role as "work which does not include work the disabled person has not asked for or which could take over any aspect of the disabled persons' own control and self-determination, no matter how small the everyday life activities this includes" (Christensen, 2010, p. 250).

Independence and dependence are also relevant to ageing and aged care, as Kröger (2009), Fine (2005), Fine and Glendinning (2005) and England and Folbre (2001) (among others) point out. Kröger reminds us that care "carries an understanding of disabled (and older) people as passive and dependent

recipients and that this makes it impossible to ... promote empowerment and an independent life" (2009, p. 399).

Dependence presents risks—but also opportunities. When a person “depends on someone else to do physical things for them, the more personal the task the greater the potential for abuse of human rights”, but also “the greater the potential for the “caregiver” to protect and promote human rights” (Jenny Morris, 2001, p. 13). Thus, several writers urge a revaluing of dependence—as part of the commonality of human experience. We “depend upon the multiple caring and interdependent relationships which exist between bodies” (Shilling, 2003, p. 22). As “relational and embodied human being[s] [we are] dependent and vulnerable” (Isaksen, 2002, p. 808). Weicht, too, disrupts constructions of dependence as burdensome, and thus to be “feared and rejected” (2011, p. 206) (and Söderberg, Ståhl, & Emilsson, 2013, critique of the risks of valorising independence):

Embracing dependency as both an interpersonal and a political project connects to Groenhout’s (2004) image of a ‘dance of intimacy’, in which both caring *and* promoting independence become possible. Although for some, an engagement with others is mainly based on being dependent, it does not follow that their not leading the dance entails an inevitable reduction in the possibility of experiencing and enjoying the social relations underlying it. (Weicht, 2011, p. 220)

The notion of *interdependence* in care has become more prominent, with Williams proposing that caring makes “one aware of diversity, ... of the need for acceptance of difference” (2001, p. 477). Herring (2007), too, considers the carer/recipient relationship as reciprocal; the carer via active caring for, and the recipient in responding with “gratitude, love, acknowledgement and emotional support” (2007, p. 68). But Herring’s formulation risks positioning the recipient as passive, or even mendicant, just as the ethic of care model’s “valorization of care overlooks the ways in which paid attendants often oppress, silence, or

abuse people with disabilities (Hughes et al., 2005; Morris, 2001)” (Clifford, 2012, p. 14).

Shifts in terminology (discussed by Kröger, 2009) countered constructions of dependence and repositioned the client as “protected from the pejorative, symbolic and practical elements of caring relationships” (p. 405). They were also linked with “a less personal, contractual relationship” (Kröger, 2009, p. 405). The next step (in the UK, and now in Australia) has been to provide disabled and older people with packages enabling them to purchase services (so-called ‘consumer-directed care’); they are employers of personal assistants.

All questions of dependence, independence and interdependence seem to position one person (the client) as receiver: the one who is dependent seeks independence or may attain interdependence. These constructions ignore that giving care, which Kittay terms “‘dependency work’, is a relationship of power with the potential to become one of exploitation (Kittay 1999)” (Fine 2007b, p. 145). For Kittay, as Kröger (2009, p. 402) notes, both parties are vulnerable—care recipients because of impairments or limitations, and care givers because they are at “risk of devaluation and domination”, as noted earlier. Shakespeare (2006, p. 142) also expressed concern at the possibility that relationships between worker and client could be “devoid of attachment and care”, and approach that between master and servant. Workers may be treated as a paid friend, or simply othered.¹² Dependence and exploitation may be masked by the bonds that can develop in support relationships (Aronson & Neysmith, 1996). Thus, contractual arrangements risk perpetuating unequal interactions, in which workers are diminished. They may also assume that the worker is independent. Yet, workers experience many things that place them in positions

¹² Woodin (2006) explored the factors shaping the development of social relationships in such arrangements between disabled people and the personal assistants they employ. In her study, construction of assistants as ‘friend’ or ‘employee’ was frequently a deliberate management strategy.

that resemble independent agency in name only. For example, although they may work alone, in clients' homes, care and support workers are bound by provider organisation policies that leave little room for initiative. They are also affected by gendered constructions that naturalise care to women and exacerbate workers' marginalisation, relative low status and (often) a lack of resources in terms of class, life chances, social, economic and cultural capital. It remains the case that care appears to be one-directional—a beneficence given by a capable person to a failing or needy other.

Citizenship

Several writers have argued for care as a citizenship or civil rights issue. Tronto (1993), for example, links giving and receiving care with becoming both more caring and moral—and better citizens (p. 167). Hughes et al. (2005) critique the ethic of care framework for neglecting the recipient of care as a citizen. The “mutuality, reciprocity and tactility [which] are the mainsprings of moral life” rely on the “subject position of the carer” (p. 264). Lawson, too, argues for the extension of thinking “beyond the theoretically and politically important notions of justice as a universal right” (p. 3). The giving and receiving of care are thus framed as rights and responsibilities of a citizen, with Morris (2001) arguing that if a person needs assistance in order to fulfil the tasks of daily life, then receiving that assistance is a civil right (see also, Jenny Morris, 2005).

The debate around gender, the market, ethics and citizenship points to a powerful undercurrent about who is, and who is not, deemed to be a citizen. Hughes et al. (2005) posit that there is a masculine, active, capable, non-subordinate, independent yardstick (subject) against which all are compared (and in so doing, othered) (cf. with Connell's hegemonic masculinity: Connell & Messerschmidt, 2005). This applies both to the low waged, low status workers, and to people with disabilities regardless of age, and is further entrenched by the emphasis placed in some current welfare regimes on work as a means of

validation (Houston, 2010; Reference Group on Welfare Reform to the Minister for Social Services, 2015; Soldatic & Chapman, 2010). The ethic of care formulation (and the naturalisation of care as feminine) incidentally positions women (carers/workers) as subordinate and 'other', since they are deviant from Kohlberg's masculine norm (justice ethics). And they work with or clean up after failures of the norm (see Isaksen 2002); in this they occupy the "realm of 'nature' ... a private domain of human activity 'beneath' the public sphere" (Hughes et al. 2005, p. 262). Hughes et al. argue that "care, like its sister concepts of love, nurture and reproduction, [was] relegated, at the outset of bourgeois modernity" (Hughes et al. 2005, p. 262). In modernity, the "'worker citizen'" (Hughes et al. 2005, p. 263) is the benchmark, and care is thus "easily discounted as a source of status or social worth because the labour of love in a rationalized, masculinized polity is, invariably, unerringly 'other'" (Hughes et al. 2005, p. 264). Hughes et al.'s (2005) formulation explains low wages and status for both workers and recipients, and depicts the care (or help) relationship as one in which *both* parties "are perpetually invalidated because the value of care is measured against the autonomous adult male who neither requires nor delivers care" (p. 265).

Being a person who neither requires nor delivers care signals agency, social rank, and power (Isaksen, 2002, p. 801). Conversely, dirt and excretions signal failure of the body and of the modern non-animal human (and see Twigg, 1997; Twigg, 2000, 2006; Twigg, Wolkowitz, Cohen, & Nettleton, 2011). Isaksen's (2002) examination of body work and perceptions of ageing and disability partly gained through images in the public discourse, brings several additional ideas about care (support) work to the fore. One is that the (body) work undertaken by workers reminds them of human fragility and mortality. The body is "integrally related to [our] self-identit[y]" (Shilling, 2003, p. 30); we identify ourselves "either negatively or positively with the 'exterior' of the

body, and [are] regularly *anxious* about the possibility that [our] body will let [us] down or ‘fall apart’” (Shilling, 2003, p. 35). But cleaning up and managing the body link the worker and recipient, raising questions as to workers’ perceptions of recipients and of themselves in attending to dirt.

One emotional response in the face of the bodily ‘failures’ of another is denial of “bodily decay and death”. The “cultural expression of denial is silence and invisibility” (Isaksen, 2002, p. 793). Workers risk biological and social contamination through their work; keeping it hidden protects both client and worker. It is also true that models of consumer-directed support put workers at risk of being othered by recipients themselves; they may experience loss of agency and increased anonymity.

Caring, autonomy and emotion

Classical sociologists “defined the human actor in terms of agency, which in practice meant the rational choice of ends” (Turner, 1991a, p. 7, quoted in Shilling, 2003, p. 24). In this light, the push for emotionally detached help makes sense, since the engaged presence of the worker may act as a reminder of the recipient’s overt need for help and/or lack of agency. If we understand meaning and identity as being emergent in “what people *do* as well as in their reflections on what they have done, are doing, or will do” (Hewitt 2003, p. 322), then being a creator of action is essential. The disability movement sides with Bauman’s “caveat (1993: 11) that, ‘the impulse to care for the other, when taken to its extreme, leads to the annihilation of the autonomy of the other, to domination and oppression’” (Hughes et al. 2005, p. 262) (and see Foner, 1994, who also reported a potential clash between worker autonomy and client wellbeing). As Benjamin puts it, one can learn to feel that ““I am the doer who does, I am the author of my acts,” by being with another person who recognizes her acts, her feelings, her intentions, her existence, and her independence” (Benjamin 1988, p. 21). So, what is the impact on workers of the demand to “enhance an

employer's [or recipient's] sense of self-sufficiency while enacting one's own self-effacement" (Hochschild, 2012, p. 158)? Recognition of the other as a subject (e.g., Bauman, 2001; Benjamin, 1988; Lévinas, 1981) is put at risk; in a master (recipient)–slave (worker) relationship, the worker is "left out of the moral equation" (Hughes et al., 2005, p. 268).

Hochschild's work—particularly the more recent exploration of the commercialisation of formerly familial intimate acts (Hochschild, 2003a, 2011, 2012)—deals with this moral equation. Her several studies (1995, 2003a, 2003b, 2011, 2012; and see Macdonald & Merrill, 2008) have focused on what she terms 'emotion work' (undertaken by family caregivers, for example) and emotional labour (undertaken as part of a paid role). She explores what this work means for those performing it (as well as reflecting upon the relationships with the 'buyers' it creates) and what it may elucidate about society more broadly. Care and support work match Hochschild's description of jobs which "call for an appreciation of display rules, feeling rules, and a capacity for deep acting" (p. 102).

Hochschild posited that workers whose role requires emotion management may 'perform' required emotions at a surface level, or 'internalise' the required emotions (what she calls 'deep acting') in order to perform care or emotional engagement (or, indeed, they may not need to perform at all). Drawing on Goffman's reflections on "the vulnerability of the marginal man and woman" (Hochschild, 2003a, p. 7), and his notion of the "public keeping of place" (Goffman, 1959/1990, p. 168), Hochschild explores feelings and feeling 'rules' in the commercialising economy of intimate life (care and support included).

Hochschild (2003a) notes that the feeling rules which govern a particular situation, and which individuals engage with continually are "not completely of their own making" (p. 97). Agency is clearly not equally available. The relative power of those involved is an important determinant in rule setting and

following, and affects both worker and recipient. The question of agency also comes into play when the capacity of recipients of support or care to perform tasks is considered; in the world of bathing, dressing and cleaning, and maintaining domestic systems, there may be appear to be nothing of which they are the creator (Hochschild, 2012). Similarly, Shilling writes that “intervening successfully in daily life, and maintaining a single definition of a situation in the face of possible disruptions, requires a high degree of competence in controlling the expressions, movements and communications of the body” (Shilling, 2003, p. 73). This is likely to be compromised for recipients of support. Thus, the “denial”, “silence and invisibility” described by Isaksen (2002, p. 793) are compounded by damaged agency. Honneth (1997) adds a further form of invisibility: that which occurs when individuals understand that their “capabilities do not enjoy any recognition” (p. 27). Both clients and workers might experience or enact this form of invisibility, since both can lack agency (understood as the power to act and exert control—Berger, 1963, p. 199). Honneth goes on to propose that there are “relations of recognition that subjects have to maintain with one another in order to secure jointly the conditions of their personal integrity” (p. 31). He includes the recognition of individual needs and the resulting duty to care among such relations. This concurs with Hughes et al.’s (2005) advocacy for making “common cause with one’s ‘fellows’ in the household of emotions” (p. 268); that is, recognizing and being in a caring relationship with people one regards as sovereign others (see Benjamin, 1988). Thus, O’Dowd can write that the “value and practice of care should have a *central place in moral theory*. Caring is one important way in which we may treat others as persons” (2012, p. 407; emphasis added).

The practice of support work is an interaction where meaning (of self, of care, of the other) emerges, is maintained and reshaped. Descriptions and definitions of care from the literature confirm this emergent and relational character (and see,

England, 2005; Featherstone, 2010; Fine, 2007a; Folbre & Olin Wright, 2012; Hochschild, 2002; Isaksen, 2002; Lappalainen & Motevasel, 1997; Wærness, 1984, 2004). Caring comprises “both social activities and emotions” (Isaksen, 2002, p. 793), and care and support interactions may be sites where the moral identity of one’s ‘relational self’ (Featherstone, 2010) can develop.

As Hochschild argues, the waged intimate work of care and the impact of power and gender on emotional responses to care or support situations is yet to be fully fathomed: “Care: we haven’t worked though it yet!” (2003, p. 7).

Conclusions

The literature reports several waves of theoretical work on the meaning and nature of care, but there has been less exploration of how care is understood by those involved in its provision. The review revealed that the largest concern of studies about care and support work is organisational (worker turnover, skills, numbers and training, for example). A second stream focusses on the experience of family members or other informal carers in providing support. Perhaps reflecting the lack of agency of either workers or clients (with the important exception of disability activists), descriptions of how these central players understand and experience care and support are less frequent. There is a dearth of literature reporting research into the meanings workers attach to practice, or how they understand their work to be valued by recipients or the wider community. The ethnographic, ‘insider’, studies are most often located in residential facilities and explore work and workers; there is less work in which the interactions and relationships between workers and clients is explored.

The relative silence of ‘untrained’ waged care and support workers compounds the invisibility of both the work and the actors. The mutuality of care and support has been touched upon, but frequently this has focused on asynchronous models in which the inevitability of every human’s need for care

and support *at some point in their life* is used to shore up arguments for interdependence. One party, at any moment, is dependent and needy; the other only *may be* at some point. Alternatively, studies have not matched workers and clients/residents in ways that enable exploration of how meaning develops in practices between dyads. To do so would require examining both workers and clients' experiences of service encounters and relationships in different settings. This review of the literature about the work of paid care and support and those involved has identified several avenues for further investigation:

- Most care and support is delivered in the community, yet studies in residential facilities are more common. Further, workers in this sector often work in both disability support and aged care roles, sometimes concurrently, and in both community and facility settings. Does their experience of work in these roles and settings differ? This focus relates to organisations, to client and worker types, and to settings.
- Care and support involves an interaction in which, arguably, meaning is made and sustained. Do workers and clients understand care and support in the same ways? What are the mutualities they experience, and what are the separating forces or understandings? (How) is 'personhood' (Byrne et al., 2013) supported? Can beneficial care and support interactions happen in the absence of a beneficent third party (Christensen, 2012), and if so, what makes that possible? This focus relates to meaning-making, relationship and the self.
- Workers and clients both experience marginalisation and dependency. How do such forces impact upon these actors and their interactions? This focus relates to how wider societal attitudes construct the lives of workers and clients.

- Care, write Fine and Glendinning (2005) is “best understood as the product or outcome of the relationship between two or more people” (p. 616). What does this product or outcome look like? This focus relates to the way care is understood (and operationalised) sociologically.

These are matters of interaction, practice, meaning, identity, and participants in aged care and disability support. They are the matters this thesis addresses.

Chapter 3.

Methodology and methods: Using an ethnographic approach to explore meaning and practice

People hanker after meanings, construct meanings, find meanings, and grasp at straws of meaning in order to *do* things, to *accomplish* ends, to *realize* objects. (J. P. Hewitt, 2003, p. 301)

Introduction

This is a study of the intersection of care and meaning in the practice of support. As the literature review showed, the voices of aged care and disability support workers are 'stilled'; their work is often invisible or discounted; the identity and meaning elements remain obscure. The scarcity of the voices and experiences of the workers and their clients has prompted this study's adoption of qualitative methods that can explore meaning and interaction and that place experiences at the centre. I want to convey what the experiences of support work are like, what care means for those involved, and what forces shape support encounters. This "impulse is consistent with a general goal of sociology to provide a forum for those whose voices are either stilled or not well understood" (Karp, 1996, p. 15). Thus, the study addresses the following research questions:

How do practice and meanings of care intersect in the delivery of support to people with disability and the frail aged?

How does practice shape meaning?

How do clients shape practice and meaning?

How are the work, the worker and the recipient depicted in public documents?

Methodological approach—Goffman's dramaturgical analogy

This study explored support and care encounters from the perspectives of both people involved. To do so, I applied Goffman's theatrical analogy (1959/1990) to the actors and their intersecting performances in aged care and disability support (an approach also adopted by Marson & Powell, 2014; Sidenvall et al., 1996b). Since much of the performance takes place 'backstage', ethnographic methods were chosen to give me a backstage pass to the world of support work, and to the scripts, sets, props and costumes of the performance. In keeping with the study's interest in meaning and interaction, symbolic interactionism (Franks, 2003; J. P. Hewitt, 2003; Scheff, 2005; Vryan, Adler, & Adler, 2003) and Goffman's work on interaction (DATE) informed the data analysis.

Erving Goffman (1959/1990, Chapter 1) drew an analogy between theatre and life. Each of us is performing; our performances, scripts and props differ according to the stage, the audience and the impression we want to create or the self we want to present. There are applicable performance rules and traditions (which Hochschild, 2003a, later reworked as 'feeling rules'). Some aspects of performance are highly public—they take place frontstage. And behind these public displays lies an array of backstage work: set construction, practice or rehearsal and training, makeup, costumes, and so forth. This analogy is particularly apt in imagining care and support work, since much care and support work takes place 'behind the scenes' in order to sustain appropriate frontstage presentations.

Marson and Powell (2014) applied a dramaturgical approach to aged care facilities, exploring how care workers who follow scripts determined by training and workplace culture can position residents as demeaned and incapable others. In their study, frontstage comprised those places where care staff and residents mixed; here, staff presented caring selves. In the backstage staff mixed with staff and residents with residents. Presentation here was

different: the mask could slip, and neglect, abuse and cruelty could more readily happen, as Twigg (2006) cautions. The backstage regions, Marson and Powell argue, “are not impression management platforms, since it would be difficult to maintain impressions if the audience could see the mess, the errors, or the practices involved in giving a convincing front region performance” (2014, p. 148).

Alternatively, though, the backstage could include those places where ‘dirty work’ involving clients and workers takes place, and frontstage all those places in or beyond the facility where an orderly or socially-acceptable self is presented. Front- and backstage may differ for workers and clients. One could cast the resident (or client) in the lead role and employ care or support workers as the stage hands or make-up artists, dressers and repetiteurs, enabling the frontstage, public performance of the client. They also work frontstage, as prompters and foils. Or workers may be presenting frontstage performances in the clients’ backstage. Figure 3.1 depicts this theatre.

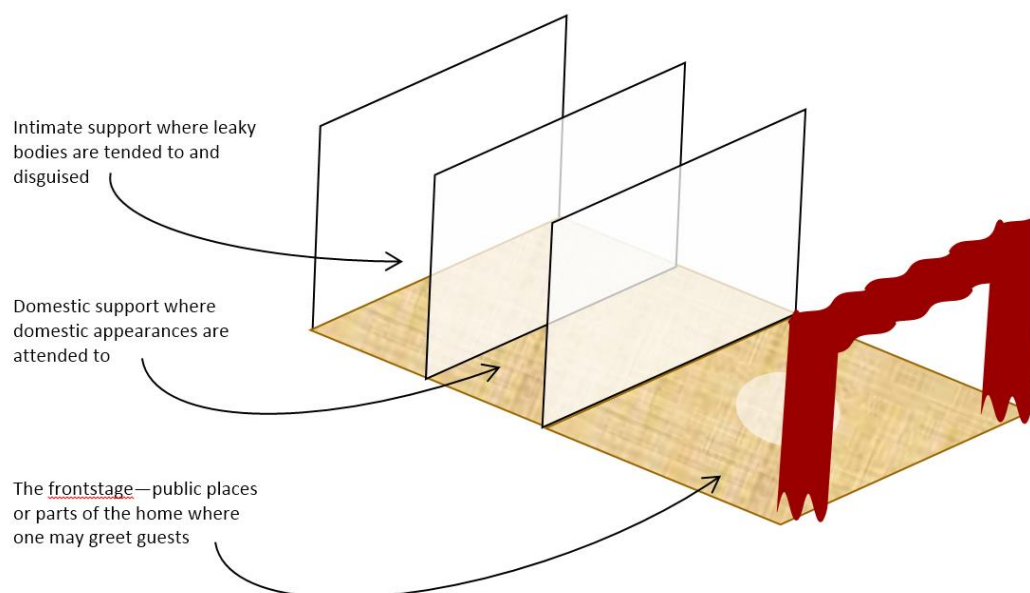


Figure 3.1. The stages upon which aged care and disability support actors perform

This research sought to understand how aged care and disability support workers and clients perceive and shape the play and their own roles, and what other forces are operating. These questions dictated that support workers and clients were the key informants, and prescribed the sorts of information that might provide views of the play from the stalls, the backstage and the actors themselves, as well as how those views might be gathered.

Performances in aged care and disability support

The ethnographic researcher endeavours to be in the privileged position of being both in the play's audience, and allowed backstage, listening, observing and being aware of the 'things' (as Smart, 2009, terms them)—the "sign-equipment" (Goffman, 1959, p. 34)—that support performances in these places.

Frontstage

Workers deliver services to clients in several settings—in residential aged or disability facilities, day centres and supported accommodation, in clients' homes, and in public settings like shops and cafés, or recreational sites. All or part of these settings may be public. Frontstage settings demand particular manners and feeling rules, created by a wider community (Hochschild, 2003a, 2011) comprising the other members of workplace teams, families or social groups, or the milieu of the public street, shop or facility. In these settings, the work—and what it creates or maintains—is on display to the public, the clients, any visiting or resident family or friends, and sometimes to other workers and more senior staff.

Backstage

The illusion required for convincing performances is created backstage. Aspects of presentation may be adjusted to ensure the appropriate or desired public impression is made. "Here", as Goffman wrote, "the performer can relax; he can

drop his front, forgo speaking his lines, and step out of character” (1959/1990, p. 115). For both workers and clients, the ‘feeling rules’ may be different and, alongside preparation and checking, some stays may be loosened. They might compare notes on their own and others’ performances (other workers, other clients), on the props and sets. Still further backstage are the workers’ and clients’ individual reflections.

Street view

The ‘street view’ has been included in this study as an additional site of meaning making. I argue that there are advance notices and posters advertising the performance, as well as critical reviews in the form of the so-called ‘grey literature’. This material includes service providers’ brochures and advertising, and news media reports on the play. The former are aimed at making sales (of services or residential places, for example) and focus on the accommodation or ‘lifestyle’ offered. The public media discourse, on the other hand, is less idealised and more widely seen. This street view (given in newspaper and online news media) provides context for the play. Seen and read by the actors and their community, these ‘reviews’ are likely to impact upon the study participants, since social identities are constructed and sustained in conversations and interactions, and in discursive contexts like public media (Haller & Ralph, 2001; Rozanova, Northcott, & McDaniel, 2006; Shakespeare, 1997; Sontag, 1990).

Using ethnographic methods to see the performance

Ethnography “is the work of describing a culture” (Spradley, 1979, p. 3). It is a means of learning from actors and their way of being in the world. Culture is constituted by meaning and meaning systems; these are at the heart of this enquiry into aged care and disability support. I wanted to explore the “complex meaning systems” workers and clients use to “organize their behavior, to

understand themselves and others, and to make sense out of the world in which they live" (Spradley, 1979, p. 5). Ethnographic studies learn about cultures by observing, listening, and "*making inferences*" (Spradley, 1979, p. 8) (emphasis in original). They can reveal both the explicit elements of the culture, and the tacit. Laying open tacit knowledge, writes Spradley, requires the ethnographer to listen, observe and study artifacts—or 'things'—and how they are used. The collection of this rich data requires sustained and direct face-to-face contact with the subjects and "intimate familiarity with the setting" (Lofland, Snow, Anderson, & Lofland, 2006, p. 16).

Working in aged care or disability support roles has provided this intimate familiarity for several ethnographic researchers (Gass, 2004; Greener, 2011; Hamilton, 2002, 2008, 2009; Lopez, 2013; Schelly, 2008). These authors had paid support roles in residential facilities or for community clients, and conducted participant observation more or less under-cover. As insiders they experienced the work and the interactions between worker and resident and between workers and other staff first hand, gaining what Goffman called 'deep familiarity' (1989). They were able to see the difference between an eye twitch and a wink, to pick up subtle emotional cues, and to sense the reason for a groan or grunt (Goffman, 1989; Lofland et al., 2006). Yet insiders also experience restrictions and may be unable to capture all the nuances of a phenomenon or setting (Mannay, 2010).

There are advantages to 'strangeness'. Unfamiliarity lends clarity, such that all is remarkable or noteworthy. An outsider, a stranger, has to learn the culture via inquiry or participation. In doing so, they may also have "a certain objectivity not normally available to culture members", since they may be able to see the "fundamental presuppositions" that shape the culture (Hammersley & Atkinson, 2007, p. 9). Familiarity—the "backdrop of communality" (Knoblauch, 2005, p. 4 of 14)—enables researchers to see obvious differences,

but in strangeness, all appears different. The stranger has license, being less likely to be constrained by overt or subtle social cues. They may wander into places that a local avoids, ask questions that are normally left unasked, and notice idiosyncrasies or patterns which are part of the taken-for-granted for those who inhabit a place (Lofland et al., 2006). Finally, strangers are unlikely to absorb habitual ways of interacting in which actors can become oblivious or only cursorily interested in what happens around them, or what is said. What the researcher thinks is worth noting is affected by this level of strangeness (see, e.g., Knoblauch, 2005).

Between insider and outsider, or familiarity and strangeness, lurks what Mannay (2010) terms the 'researcher near' and Knoblauch (2005) 'alterity'. This approximates my position.

Methodological reflection

Symbolic interactionism and the dramaturgical analogy are micro-sociological approaches. That is, they focus on behaviour and meaning in small-scale interactions between individuals. They have been criticised as emphasising the trivial and ignoring wider macrosociological concern with structural forces. Gouldner (1970), for example, argued that Goffman's approach glosses over how structural forces affect individual performances, or the link between corporealities and wider social norms of body idiom (Shilling, 2003, p. 77).

Yet, investigating and reporting on the microsociological can alert us to the sort of social stratification and power-plays that Gouldner (1970) argued were ignored in Goffman's methodology. Collet and Childs (2009), in applying the dramaturgical approach to study of the family, argued that it is "through performances that social reality—including selves and the social world—is created" (p. 690). That is, social structures like family, religion, class and so forth can be argued to be the product of multiple 'meaning-creating'

performances and interactions, which can be examined microsociologically. Social interactions can, thus, have “crucial implications for huge numbers of people”, and “Goffman’s work should inform our understandings of structural concerns” (Shilling, 2003, p. 77). Indeed, Goffman’s work on institutions (Goffman, 1961a, 1961b) played an important role in the deinstitutionalisation of people with disabilities (Fine, 2007a; Manning, 1999). The ‘mortification of the self’ described in *Asylums* (1961a) was only made visible by Goffman’s attention to numerous individual interactions.

Arlie Hochschild’s work extended Goffman’s symbolic interactionism, examining how institutions influence or control us through surveillance and control of feelings. She (2003b) critiqued Goffman’s belief that “the capacity to act on feeling derives only from the occasion, not from the individual” (p. 228). As Freund put this, the “ability to manage one’s self-presentation can be short-circuited by structural conditions” (2015, p. 167). The unearthing of the microsocial world is essential if we are to understand how structural forces affect individuals in their various roles.

The dramaturgical analogy—in casting individuals as actors, engaged in an almost constant performance of impression management—has been described as positioning people as cynical actors, manipulating others through impression management techniques (Gouldner, 1970; Manning, 1991). Actors “accentuate some aspects of their performance while concealing others” (Manning, 1991, p. 76). Gouldner (1970)—perhaps the most staunch critic of Goffman’s approach—argues that distinguishing cynicism from sincerity is made difficult. The theatrical analogy “blurs the distinction between the morally sanctioned and non-sanctioned, and between those behaviors fabricated for the moment and those that are integral, habitual, appropriate, and sanctioned and perceived by all to be so—those constitutive of who I am” (Wilshire, 1982, p. 294). People ‘work the system’ for their own ends, rather than being part of a social order.

The “actor’s artistry” is, thus, “a kind of deceit” (Wilshire, 1982, p. 291). Nevertheless, the theatrical analogy acknowledges that performing is “inescapable in most of everyday life, and to “perform” effectively as *persona* performed we must more or less mask” aspects of ourselves (Wilshire, 1982, p. 297) (emphasis in original). The reasons for such performances or deceit are, in their own right, important. After all, we can learn a great deal about meaning for the actors from the impressions that they are working to manage (Geertz, 1983; Goffman, 1959/1990).

I had research experience of care and support provision as well as relationships with people involved directly and administratively in paid support relationships. It was, nonetheless, necessary to “mak[e] the familiar strange” (Mannay, 2010, p. 93), and question my assumptions. One assumption, was that I was a sort of physical, social and cognitive expert. I was going into participants’ lives *as if* I were a person who ticked many capacity and life chances boxes. Yet reflection made it apparent that I was simply a variant of the people recruited, and they variants of me. I paid attention to relative power in our interactions and to the methods, and “autobiographical details outlining [my] involvement in the social situation” (Burgess, 1981, p. 76, Newbury, 2001, p. 5 of 17). The varying social situations demanded that my role shifted as the study progressed, and that reflection was a constant part of my research practice.

I also wanted to maintain alterity. I kept my distance from provider organisation administrators. They distributed fliers and posters to workers and/or clients, but I was careful not to align myself with them, and had no further contact after initial meetings or emails. I chose the language and self-portrait for the recruitment fliers and posters (see Appendix A) with the

intention of both maintaining that distance and playing my role as a serious but non-threatening actor.¹³

Three 'stages' and an ethnographic methodology

Goffman's dramaturgical approach was chosen to frame the performance of aged care and disability support work. This framework enables the scripts, performances and sets as well as the street view of the encounters between workers and clients to be seen as connected elements in the emergence and maintenance of meaning. A dramaturgical approach also takes into account the performance and role of the researcher. Operationalising this methodological framework through ethnographic methods required capturing the scripts and actions, as well as the interplay between performers and between performers and objects.

¹³ Staff in two organisations—a disability services provider and an aged care provider—gave me valuable advice about the language and layout of these fliers. I am grateful to them.

Methods

Questions of insider and outsider status shaped the recruitment of participants, as well as the way interviews and observations were conducted and recorded.

Recruiting the participants

Goffman advises that “your job is to get as close to some set of individuals as possible” (1989, p. 129). I wanted to get close to aged care and disability support workers and their clients. I had not worked as a support worker, nor been a client. But I had some experience which made me suspect that ‘researcher near’ status had some benefits. In previous research work in aged care facilities and Aboriginal health services I had seen insider actors respond defensively to the arrival of ‘expert’ outsiders. When I introduced myself as a person with little knowledge of the work that they knew intimately or of the morbidities they dealt with, workers’ physical signals of defence disappeared and the conversation flowed.

These manoeuvres were mirrored in my first meetings with potential worker participants in the present study. They sought “to place or locate [me] within the social landscape defined by their experience” (Hammersley & Atkinson, 2007, p. 63), often making overt or veiled enquiries about my background: was I a nurse, or a social worker, or perhaps I worked in a big provider organisation or for the ‘Department’. I had ‘impression management’ (Goffman, 1967) to do. My accent, lexicon and role indicated a particular social niche,¹⁴ but I followed the actors’ lead, using forms of address dictated by them, for example, and attempting to choose language that did not separate us.¹⁵ ‘Doing similarity’ (Abell, Locke, Condor, Gibson, & Stevenson, 2006) via “interviewer self-disclosure may prompt reciprocal talk on the part of the respondent, especially

¹⁴ Though my very noisy old car seemed to be an asset.

¹⁵ Transcribing assisted in this, as the stultifying impact of any poorly chosen words or expressions, and of talking too much, was readily apparent.

in relation to potentially ‘delicate’ matter (Jourard, 1971)” (Abell et al., 2006, p. 223). It can, however, backfire, when it implies the interviewer’s “greater category entitlement” (Abell et al., 2006, p. 241) or greater power over the topic. My questions about what to the worker were pieces of basic knowledge—about procedures, or equipment, for example—restated their expert status and seemed to lead to much more free-flowing conversations.

While a ‘novice’ role was not available to me (Hammersley & Atkinson, 2007), I tried to remain alert to the status alignments of (potential) participants during recruitment and data gathering (Goffman, 1989).

Participants. The cast of the play

Getting in: Recruitment, organisations and researcher status

Obvious connection with provider organisations risked creating a study group of participants who were themselves aligned with organisations, or who would be unwilling or unable to be “*sensitive to the area of concern*” (Hammersley & Atkinson, 2007, p. 106) (emphasis in original), due to their suspicion about my allegiance. Thus, I was attentive to social relationships and status (Goffman, 1989). I had a face-to-face conversation with the CEOs or managers of a large number of aged care and disability support provider organisations, seeking their permission and access to a facility, noticeboard or newsletter (for advertising for participants) or to gain permission to present a recruiting talk to staff or clients. After that, I had no further contact with provider organisations.

To further distance myself from provider organisations—and reduce the risk of recruiting a participant cohort too dense with the “more-willing-to-reveal” (Hammersley & Atkinson, 2007, p. 106)—I proposed snowball sampling (Walter, 2010), and recruiting workers via unions. Four strategies for participant recruitment were used; some were spectacularly unsuccessful. Table 3.1 sets out the strategies and outcomes.

Table 3.1. Recruitment strategies and outcomes

Participant	Strategy	Method	Outcome
Worker	Via relevant national and local unions (HACSU, ASU)	Letters, emails and telephone calls to unions: <ul style="list-style-type: none"> • Providing outline of project • Requesting opportunity to discuss and to advertise for participants via union publications/web site 	No response to any correspondence or telephone calls.
Worker Client	Via people known to the researcher	Personal approach to existing contacts in work or client roles	2
Worker Client	Via already recruited participants (snowball sampling).	Invited existing participants to pass project fliers (see Appendix A) to other workers or clients (worker to worker and client to client only)	2
Worker Client	Via employer/provider organisations	Letters, emails and telephone calls to managers within provider organisation: <ul style="list-style-type: none"> • Providing outline of project • Requesting opportunity to discuss and to advertise for participants via newsletters and noticeboards (see Appendix A) • Requesting opportunity to speak to staff at morning or afternoon tea breaks 	17
Worker	Via client participant	Client participants invited support workers to become part of the project, providing them with fliers and information and consent forms	8

Organisations put fliers in staff pigeon-holes and in mail outs to clients, and gave me permission to pin posters on noticeboards. The fliers and posters all included a photograph of me. This was intended to make first meetings simpler, and to personalise the research. I also gave morning tea and change of shift talks to care and support staff and client groups in residential and day centre settings.

Ethics, study design and recruitment

Data was gathered using interviewing, observation and photo-elicitation. Interviews were relatively straightforward to arrange, involving a 'contract' between researcher and a single informant. Observing how workers and clients interact during care and support, and involving them in photo-voice data production both presented ethical challenges.

Observation and photo-voice required that both worker and client in a service encounter had consented to be involved in the study. Photographs taken by participants could not include non-participants. In facilities, multiple residents and staff are usually present. Gaining the consent of all those present or those who may arrive during an observation period presents logistical challenges. Some elements of care or support are carried out in what are essentially frontstage settings, and the remainder in settings which might be described as only semi-private. Doors of bedrooms and bathrooms are often left open and more than one staff member—and more than one resident—may be present. Other residents, only some of whom would be able to consent, might interrupt. It was clear that I could not control who might be present during observation of work performances in such circumstances, and that those taking photographs would face similar challenges. In-home service encounters, on the other hand, provide a clearer environment. Here, the worker and the client are often the only people present. For these reasons, I recruited two groups: a group of workers who would be interviewed individually, and a group of client:worker dyads who would be interviewed separately, observed together and who would be invited to make photo-voice images to be used as prompts in later interviews.

Gaining ethical approval meant accounting for power and vulnerability the research could spark or exacerbate. Ethics forms and processes often flatten the differences between people with disabilities, group them as if all the same, and

then categorise them as being vulnerable; this was certainly the case for the particular ethics guidelines this study needed to meet (NHMRC (National Health and Medical Research Council, 2007). I disagreed with this construction of people with disabilities,¹⁶ and was concerned that it could translate into an excuse for their exclusion from the study. I gave control to clients in the project dyads by inviting them to recruit the workers (Ahlström and Wadensten also recruited personal care workers, though less directly, through clients; 2010, 2012). Clients were self-selecting rather than being 'encouraged' to be part of the project by workers or organisations. The ethics committee questioned my proposal to give dyad members the same information and consent forms (Appendix B), arguing that clients were indeed vulnerable and would experience greater risk of shame or embarrassment than workers. But this perspective overlooked research showing that workers too experience feelings of embarrassment and shame and that body work is associated with very low status (e.g., Isaksen, 2002; Twigg, 1997a). Ethics approval for the project was granted by the Tasmanian Human Research Ethics Committee (H0013031).

Meeting the participants

The first call I received was from Cornelia, who lived in an independent living unit attached to a residential aged care facility. After her, Ruby emailed me, then Stella and Evelyn and so, in all, thirty people volunteered to be part of the study. I excluded only one: she worked in a specialised support role in a small organisation. Hiding her identity would be impossible.

Prospective participants called, emailed or texted (SMS) me to express interest (see Appendix C for examples of first contacts with participants), or spoke to me after talks I gave. Preliminary meetings were arranged at times and places

¹⁶ Andrea Hollomotz (2006, p. 2) has made the case that "'vulnerability" is a concept that is socially created and socially creating".

chosen by the potential participant. Two initial meetings took place at a supported facility, and two at the participants' non-support work workplaces; the remainder were in cafés or where the person lived or worked. I met Brian, Lilla, and Miriam, and Justin, Gerry, Erica and Sharon together; otherwise, all preliminary interviews were one to one. At our first meeting, which was recorded using note-taking only, I provided Information Sheets (Appendix B); I sometimes read the sheet aloud, or gave a verbal outline. I explained the project and activities in detail. I checked to make sure that potential participants understood what they were being invited to do,¹⁷ the sorts of topics I was interested in, and that they could choose to not answer questions or to withdraw from the project entirely at any time. I then asked for signed or verbal consent (Appendix B).¹⁸ I gathered some basic demographic data, and we set the time and place for the first long in-depth interview. The chart below (Figure 3.2) illustrates the timing of recruitment between May 2013 and March 2014.

¹⁷ In accordance with the ethics approval for the project (H13031), all relevant elements of the project were explained to each potential participant and I checked that they had understood what was involved (a process guided by the *Tasmanian Capacity Toolkit* (2008)). Some organisations providing services to people with learning difficulties or who could not read, distributed fliers to clients deemed to have capacity to consent—erring in the direction of capacity rather than incapacity. The organisations were not told whether any of their clients had joined the project.

¹⁸ Four people gave verbal consent.

Information Sheets. One contacted me the next day and the other asked that I talk with a member of his support team. All three people joined the study. Similarly, four people were recruited when I spent time in a group house. The remaining participants contacted me as a result of having seen my fliers or posters. Appendix D details the links between participants and provider organisations.

The participants

Twenty-nine people joined the study. Twenty were members of client:worker dyads and there were seven workers and two clients not in dyads (see Table 3.2).

Table 3.2. Participant group members

Worker	Vic, Lilla, Tash, Jai, Ruby, Miriam, Tilda		Client in dyad
	Stella	& Raphael	
Worker in dyad	Brian	& Bill	
	Edwina	& Laurence	
	Leonie	& Nicko	
	Blanche	& Fred	
	Joanna	& Olivia	
	Shirley	& Winifred	
	Sharon	& Erica	
	Justin	& Gerry	
	Anita	& Sally	
	Cornelia, Norah		Client

The un-paired clients both lived in forms of supported accommodation and invited workers to join the study, but their invitations were declined. I speculate that staff working in highly supervised settings were unwilling to

take part in the observation element of the project (since several of the worker-only group—for whom no observation was involved—worked in facilities) precluding them from being part of a research dyad. This was a weakness in the study design.

As participants entered the project, the inadequacy and inaccuracy of the formal labels of ‘worker’, ‘aged care client’, ‘person with disabilities’ became apparent. I was frequently shown evidence of the possibly infinite potential classifications, the border-lands, and liminal states (Kumari Campbell, 2009) that people occupy. There have been many approaches to the dilemma of categorising this presents, and much discussion about the problems with such categorisation. Shakespeare (2014a, 2014b), while supporting the notion of disability as being socially created (Oliver, 1983, 1990), also states that impairment is real and creates difficulties (pain, physical restriction, etc.) which are unrelated to the social or physical environments. Further, as data gathering for the present study progressed, it became clear that distinctions between workers and clients based on capacity or incapacity, non-disabled or disabled state, were sometimes arbitrary (Appendix E is a discussion of this finding). Indeed, Kumari-Campbell calls into question “the notion of abled(ness)”, and the “compulsion to emulate ableist regulatory norms” (2009, p. 1). The participants are introduced in Chapter 4.

Recruitment constraints

While both clients and workers told me horror stories about bad worker practice, only one participating worker seemed to be directly involved in such practices. The experiences reported to me overall, then, reflect only a slice of the world of care and support; gaining a warts-and-all picture would require a different recruiting strategy.

Participants in this study included a retired headmaster, a couple of former senior public servants, two students, an activist, people with medical backgrounds, or with significant research skills, two people who had been very well-known in their fields, and several former executives. They cannot be said to have made up a representative sample of workers or clients in disability support and aged care services in Australia. As a self-selected group, this was to be expected, but recruiting was also shaped by two restrictions. The first was that all participants had to give their own consent. The second was that I used mostly visual material to recruit participants (posters and fliers), which limited who was likely to respond. There was no one in the study who had complete vision loss, or who had an impairment that made speaking or hearing very difficult, and no one with a cognitive impairment that severely affected executive function or comprehension. Ideally, a study of this sort would include a wider range of participants.

Client participants had several things in common. With the exception of Bill, none of the clients was in a romantic/partner relationship; several were widowed or divorced or had lost long-term relationships. Further, they were mostly capable and proactive; they were often well educated and the places they lived in were pleasant and well-maintained. There was a sense that the clients felt competent, like ‘good examples’ and that they had something to say. After meeting Laurence for the second time, I noted that:

the people who wanted to be in my project (recipients certainly and some workers) are people who want to make a difference and who have some capacity to do so. They see this as an opportunity to push for something that matters to them.

This seemed especially true for Olivia, Evelyn, Bill, Sally, Cornelia and Laurence, all of whom lived in the community. Olivia, for example, saw participation as an opportunity to explore her own understanding and conception of care and support. Evelyn, Laurence and Cornelia all gave me notes they had made about care and support, and Evelyn in particular followed

the process avidly, often talking about methodological matters with me. For Laurence, the project represented, in part, an opportunity to be an activist or advocate.

This activist streak also seemed to be present in some of those who worked in facilities or the community. Brian, Jai, Ruby, Joanna, Tash, Leonie, Lilla, Shirley, and Vic had stories they wanted told about the work they did, the people they worked with and the organisations that employed them. They wanted change—good practices needed to be talked about to encourage their spread, and bad practices to alert others to the need for change.

Informants fitted the two participant categories identified by Hammersley and Atkinson of “especially sensitive” and “more-willing-to-reveal” (2007, p. 106). As they warned, the voluble enthusiasts did indeed dominate. This was evident to some extent the first time we met, and sometimes from the first phone call or email. One person, for example, started our engagement by sending me a collection of stories they had written about the loss of personhood in aged care.

The data

Interviews

Listening in this study took the form of repeated semi-structured non-directive interviews and incidental conversations with both workers and recipients in and away from work settings. I also listened during observations.

Spradley (1979) says that the questions we follow must arise from the informants’ culture, and that there is a risk that predetermined questions will “predefine what respondents will report and do not necessarily tap into the cultural knowledge” they hold (p. 32). Such “culture-bound questions” can “prevent discovery of the other person’s point of view” (p. 32). For this reason, interviews were non-directive—an approach that derives from naturalism—and used thematic prompts (Hammersley & Atkinson, 2007). In later interviews, I

used images created by participants or from the public documents as prompts (Appendix F).

Participants were eager to talk. At the start of each interview, I provided an outline of the topics I was interested in (see Appendix G: Interview protocols) and thereafter occasionally drew participants back to the topics:

- workers'/clients' perceptions of themselves in this role
- workers'/clients' perceptions of their clients/workers
- what workers/clients do
- how the work is seen by others.

Usually, inviting each participant to talk “at length in his or her own terms” (Hammersley & Atkinson, 2007, p. 101) resulted in interviewees providing very thorough coverage of the topics in which I was interested. The non-directive approach meant that interviewees’ word choice and thinking were not unduly influenced by me, with the exception of my intrusion—reported later—into a conversation with Brian and Miriam. Nonetheless, non-directive approaches cannot prevent participants from suspecting what the researcher is after. They may, as a result, tell you the story they think you expect to hear, or repeat the public version of events. Equally, the ‘more-willing-to-reveal’ may have a message or performance they want to give to their new audience. I sought to minimise these risks by conducting repeated interviews with most participants (and see Hammersley & Atkinson, 2007, Chapter 5). Repeated interviews allow for the revelation of things that “may be masked in everyday interaction” (Lofland et al., 2006, p. 18), and was intended, too, to enable trust to develop (McNamara, 2009; Spradley, 1979). I wanted participants to trust me (and see Birch & Miller, 2000). There was some evidence that my use of repeated interviews increased trust. In our first interview, one participant had a distinctive way of beginning sentences: “*Can I tell you something?*”. This phrase, and slight variations of it, appeared 35 times in the interview transcript. The

number decreased in our second interview, and in the third (final) conversation, then phrase was used three times.

Trust, communion (Ezzy, 2010) and disclosure (Harris, 2015, provides a particular rich exploration) were important for the interviews. I was open about myself and my experiences, and about my lack of practical knowledge of support work. I explained when we first met that I had no support or health training, and no experience of being supported, enabling participants to thus assume their own expert status.

Interviews were informed by the topics and any previous interviews and observations (Hansen, 2001); for example:

Thanks for talking to me last time—that was really valuable. I wonder if I could ask you about a few things that came up when we were talking/that I noticed when I was here as an observer, to see how you see them?

This process formed a sort of member checking. Dobbs et al. (2008) argue that repeated meetings enabled participants in their study to expand on their responses, as well as “providing opportunities for a deeper examination of some topics, which also contributed to the trustworthiness of what [they] heard and learned” (p. 520).

A further form of checking took place at two points in the project. After three months and again after fifteen months of interviews and observations, I prepared a short report, setting out what I had been doing and some of the themes that were appearing in the data (Appendix H: Project reports). Every participant currently in the study was given a copy of the reports. I gave a verbal account of what I was finding and how I was thinking to people who were unable to read (2 people). The reports prompted additional discussion—and sometimes revision—of the emerging themes

Process

Of the 29 participants in the study, there were four to whom I spoke only once. The remaining 25 were interviewed at least twice, and some up to five times. There were also many informal conversations, where the participant telephoned me for a chat, or sent emails or letters.¹⁹ In some cases, we also met casually (without the recorder) in cafés and talked over cups of coffee. The very free-flowing nature of these interactions had an additional function as sites of presentation of self and ‘face work’ (Goffman, 1967). I made written notes during and after the first interviews and any informal conversations, and audio-recorded, with permission, all other interviews.

On recording

Because the details and nuances of language use are important (Hansen, 2006; Spradley, 1979; Travers, 1997) and it is not practical for the researcher to make sufficiently accurate records of what is said in interviews using pen and paper, I digitally recorded and subsequently transcribed the material verbatim.²⁰ I asked for permission to record each interview and switched the recorder off when asked (this happened very rarely), when phone calls interrupted or when other people entered the room. Recording allowed me “to invest more time in inquiring, interviewing and retrieving background knowledge” (Knoblauch, 2005, p. 9). I noted gestures, verbal ticks, laughter, sighs, inflection changes, and other signals, both in fieldnotes and as I transcribed, in order to avoid missing relevant signals of meaning or emotion (Travers, 1997).

¹⁹ Material from emails or letters was used as prompts in subsequent interviews or conversations with the sender. I gained permission to record one long, spontaneous telephone conversation.

²⁰ I removed identifiers from the material as I transcribed. I created a spreadsheet, kept separate from the data, in which people, organisations, places, businesses and other identifiers and their pseudonyms were listed.

Observation

The ultimate behavioral materials are the glances, gestures, positionings, and verbal statements that people continuously feed into the situation, whether intended or not. These are the external signs of orientation and involvement—states of mind and body not ordinarily examined with respect to their social organization. (Goffman, 1967, p. 2)

Observation is an opportunity to see how the performances, described in interviews, look and to discern the function of props and settings (Goffman, 1959/1990). Goffman (1989) described observation as the researcher placing themselves in a position to “physically and ecologically penetrate [the subjects’] circle of response to their social situation, or their work situation ... So that you are close to them while they are responding to what life does to them” (p. 125). This is not, he continues, just to hear what they talk about, but “to pick up their minor grunts and groans as they respond to their situation” (p. 125)—to “sense what it is that they’re responding to” (pp. 125–126). Hammersley and Atkinson (2007, p. 62 ff) discuss Goffman’s advocacy for ‘civil inattention’—the performed disinterest or disengagement which provides a sort of anonymity to the social actors in a setting. Taking this advice, I tried to ‘become part of the furniture’, withdrew when intimate personal support took place (e.g., assistance with bathing), and avoided eye contact.

Process

I observed at least one service encounter—from the time the worker arrived—for each of the ten dyads. Observations usually took place after one or two interviews had been conducted with the participants,²¹ with the client suggesting the observation time. Then the client and I independently checked with the worker that it suited them. This checking was intended to reduce the risk of one or other person feeling pressured.

²¹ I met one worker for the first time when the client (with the workers’ permission) invited me to observe them together, and the same happened with four people (2 dyads) I observed and interviewed at their group home.

Most observations took place where the client lived. I generally arrived, by agreement, before the worker and, having explained that I would try to remain unobtrusive and that either person could request that I leave the room or leave altogether, found a place to sit that enabled me to watch interactions. Some pairs were very active, moving around the house together or separately; I usually followed. I also accompanied one dyad to and from the shops and 'shadowed' them around supermarkets, department stores, a café, the post office and newsagent.

Being unobtrusive is, of course, impossible, and that participants found the idea of my being unobtrusive slightly risible was clear. All made remarks about my presence. Cups of tea were sometimes offered to 'the shadow' or 'the ghost in the corner', but the same apparent civil inattention (described as "minimal eye contact, careful management of proximity, and so on", by Hammersley & Atkinson, 2007, p. 43, citing Goffman (1971)) that I was using, and a sing-song tone adopted. Chocolate biscuits were counted out to make provision for the ghost, and left nearby. A photo of the proffered chocolate biscuits was part of their photo-voice gallery. With another, discussion of my observations included him joking about potential thesis titles, including "*There's no such thing as 'yeuch'*" and "*I'll just lift my feet*"—references to the cleaning up and vacuuming around human 'obstacles' like me and him that I had observed.

On recording

Write [your fieldnotes] as lushly as you can, as loosely as you can, as long as you put yourself into it, where you say, "I felt that." (Goffman, 1989, p. 131)

I took notes in a chronological, comprehensive (Wolfinger, 2002, pp. 90-91; and see Newbury, 2001) manner so that otherwise taken-for-granted elements would be more likely to be recorded, and to build up a picture of the applicable norms (Wolfinger, 2002, p. 91). This could enable the identification of deviant cases—for example, when something that has occurred in other observations

does not happen—and is congruent with Hammersley and Atkinson's (2007) suggestion of recording "even things that one does not immediately understand, because these may turn out to be important later" (p. 143).

I also decided to write all of the time. This was contrary to Hammersley and Atkinson's warning that in some contexts, "open and continuous note-taking will be perceived as inappropriate or threatening, and will prove disruptive" (2007, p. 143). My stance was intended to avoid drawing *additional* attention to my role or to the action I was watching through sudden bursts of writing associated with particular moments. My writing was, nevertheless, commented upon:

Raphael asked me what I had written down so far and I said I was just noting down that Stella had given him toast and was now vacuuming; Stella and I had a discussion about how to spell 'vacuum'. Raphael said "H O O V E R". (Fieldnotes)

I also paid attention to the setting (Hammersley & Atkinson, 2007), something Hochschild does rigorously (see, for example, 2003a, 2012). I usually made a sketch of the room and the layout of the person's home (whether private house or shared facility) and marked the participants' positions and movements—in particular when they engaged in conversations (I also wrote down remarks verbatim). I recorded how close to one another they were, and whether the pair made eye contact, or moved to be at the same eye-level. I was also (increasingly) alert to their gestures, tone of voice and physical contact. These elements were then used as discussion prompts/topics in subsequent interviews. Appendix I gives some examples of the maps and sketches.

Visual methods

Things are invested with meanings and a focus on things (such as photographs or keepsakes) can allow people to speak about subjects that

matter to them and in a way that is less formal than in the interview context. (Smart, 2009, p. 301)

Photo-elicitation (and see Brand & McMurray, 2009; Harper, 2002; Mannay, 2010; Mason, 2005; Oliffe & Bottorff, 2007; Ortega-Alcázar & Dychk, 2012) is a way to make visible things that may not be apparent in observation, or mentioned in usual interview processes. I used photographs as interview prompts, to “*cross cultural boundaries*” (Harper, 2002, p. 21) (emphasis added). Photo-elicitation “may overcome the difficulties posed by in-depth interviewing because it is anchored in an image that is understood, at least in part, by both parties” (2002, p. 20). Further, there are layers of meaning in images—from the apparent, to what processes are implied or shown, to “the values that were represented in the actions that surrounded the object” (Harper, 2012a, p. 158). Images could raise questions that other information or avenues of enquiry did not throw up (Grady, 2008), and participants may discuss what else might have been included—what is beyond the edge of the frame (actually and metaphorically).

Pictures may be the most intimate, spontaneous, candid and personal images or be carefully set up to create a particular impression. They “have many lives and can sustain quite varied, if not divergent, meanings” (Grady, 2008, p. 8 of 34). In Oliffe and Bottorff’s (2007) study, men recovering from prostate cancer surgery made apparently impersonal photographic images that had symbolic emotional power undiscernible to a casual viewer (e.g., a photograph of a garden seat, which represented the photographer’s fatigue and incapacity to garden) and highly personal images of their own changed body (e.g., naked and wearing an incontinence pad).

I used two sorts of images in the present study—photographs taken from public sources, and participant-generated images.

Public images

I wanted to explore how the work, workers and clients were constructed in their local context, since such public texts “construct and sustain particular social identities” (Fealy, McNamara, Pearl Treacy, & Lyons, 2012, p. 99) and may shape support interactions. Local newspapers, for example, can be “fuzzy indicators” (Franklin & White, 2001, p. 225) of the milieu in which participants operate. The language (including images) is “rarely neutral ... Events and identities are constructed through journalists’ and other stakeholders’ values, social languages and interpretive repertoires” (Fealy et al., 2012, p. 94).

Perceptions of older people—gained in part via public images—have been found to be reductionist and general, robbing them of individuality (Isaksen, 2002). Ageing, like disability, is a socially constructed category (Rozanova et al., 2006), a product not only of biological processes, but of “social interactions and power relationships in society” (Powell & Hendricks, 2009, p. 85). Two constructions are prevalent: older people as healthy, active and engaged, or unhealthy, inactive and poor (Rozanova, 2010; Rozanova, Miller, Wetle, & Mor, 2010; Rozanova et al., 2006). Regardless of category, they are “different from and unequal to younger adults” (Rozanova et al., 2006, and see Fealy et al., 2012, p. 88).

Gender constructions also shape media portrayals of both older (see, for example, Rozanova, et al., 2006, and Fealy, et al., 2012) and disabled people (Gold & Auslander, 1999a; Shakespeare, 1997). Lois Keith found a disempowered and submissive ideal in depictions and meanings of disability, illness and death in fiction written for girls (2001). Block (2000) labelled this the “heroic Cinderellas” model (p. 250) in her analysis of news media portrayals of the sexual identities of women with intellectual disabilities. The alternative construction was as a/immoral, “demonic succubae” (p. 250). Disability was a grab-all category, with individual characteristics 'subsumed' 'beneath a

designation of pathology" (Block, 2000, p. 240). A further stereotype appears in the metaphorical use of demeaning portrayals of disabled people in messages linking risk (and injury) with stupidity and blame (Wang, 1998). In other words, disabled people and older people are often essentialised in media as *all* being other. Taking this further, Shakespeare (1997) suggests that 'able' people may paradoxically like having the disabled (or old) to compare themselves with and to act as repositories for generosity and compassion.

Such constructions enable the maintenance of a "cycle of discrimination and abuse" (Block, 2000, p. 251), and put the unfamiliar at a 'safe' distance (Shakespeare, 1997 citing Barthes), obscuring "the reality that people with cognitive disabilities do not live sealed off within their own joyfilled worlds, oblivious to cultural perceptions" (p. 251). That closeness to people with illness or disability threatens our ignoring/ance of frailty and mortality is posited by Shakespeare (1997), Twigg (2000b), Boleyn-Fitzgerald (2003), Isaksen (2002) and Weicht (2011). But objectification (Shakespeare, 1997, p. 7) results in the subject's own sense of self being supplanted by someone else's view, adversely affecting the social construction of identity (also see Scholl & Sabat, 2008). Media portrayals were likely to be important in attitudes towards (and identity formation for) clients in the present study.

The richness and complexity of the lives of older and younger people with disabilities are missing from public portrayals, but researchers have been attentive to this form of stigmatising construction. There has been no equivalent analysis of how workers are constructed. Hochschild (2001) traced a 'global care chain' of care workers, yet analysis of media portrayals of health worker migrations has focused on doctors and nurses (Pylypa, 2013), echoing Seale's (2003) finding that these professionals dominated all media on health workers. Nonetheless, images of workers, clients and the work appear across public

documents—in newspaper articles, policy documents and the brochures of provider and client organisations.

My earlier searches of online image banks returned photographs (usually from advertising for provider organisations) that minimised the body/dirty work aspects of the role, and depicted workers who were far from typical (being young women, for example) and clients who appeared powerless and grateful. The most prevalent image ignored the person altogether (see Figure 3.3). Newspapers and online news sites, on the other hand, had often negative stories—and images—of care and support.



Figure 3.3. Generic young-hands-old-hands image

I collected images of the work, workers and clients from brochures and provider web-sites, and from local news media, to use as interview prompts. I speculated that workers might draw a blank, see the material as ridiculous, or

prompt them to repeat the public versions of events.²² I hoped their use would also give workers expert status in the interviews. This was indeed the case, as the results chapters reveal. In addition, I undertook a descriptive review of news media portrayals of disability support and aged care work, workers and clients to ascertain the local public discourse context of the present study. The review and results are discussed in Chapter 4.

Reservations and limitations

There is some suspicion in social science that images are not a trustworthy data form, since they have links with entertainment and with persuasion (propaganda) (Mason, 2005, p. 329). Selection and interpretation, too, are risky since the “narrative produced is based upon such a selection” (Mason, 2005, p. 329). I have adopted Prosser’s (1998) solution of using and discussing the public images as data, with participants controlling what was included and what rejected.

Participant-generated images—photo-voice

Participant-generated images provided an opportunity to add depth and complexity to the typical public image described above, and gives participants the opportunity to “counter the tacit and normalizing effects of knowledge, which operates by taking one’s group experiences and assuming these to be paradigmatic of all” (Mannay, 2010, pp. 107-108). The process is also a way to shift the research relationship towards equality, since the participants have control over content and perspectives and greater control over the subsequent

²² I included a typical young-hand-old-hand image (Figure 3.3) in the photo-elicitation. The people who commented on it seemed to immediately shift into ‘caring’ mode. Tilda, for example, had been fairly brusquely discussing a distasteful aspect of food preparation but became sentimental: “*That’s nice. There’s a song by Geoff Bullet called, “When weary hands were young”. Beautiful song. Those weary hands were like that once. And they too will become like that”*.”

interviews (Harper, 2012b, 2012c; Mannay, 2010, p. 101). Authority rests with “the subject rather than the researcher” (Harper, 2002, p. 15), in keeping with non-directive interview strategies.

Process—photo-voice

Each dyad was invited to photograph the work. Three dyads agreed and I provided these six participants with digital cameras, and showed them how to use them and how to view (and discard) images. We also discussed the need for both dyad members to agree to any photograph being taken. Data from only two dyads were used; the members of a third dyad received cameras, but one person in that pair died. The cameras became part of the ‘chattels’ dealt with by her executor and were lost to the project. The remaining pairs produced sets of images that proved highly evocative of their relationships; some are included in the results chapters. Once dyads decided they had completed this part of the project, I collected the cameras, colour printed (A4 size) and laminated the photos and marked on the back who had taken them and when. I then took them to dyad-member interviews, having gained each person’s permission to share the photographs with their dyad partner.

Photos as prompts

In interviews, I spread the prompt images out and asked the participant if they wanted to comment on any. Sometimes I asked for more information, using questions like “*What is this?*”, “*What are you/they doing in this photo?*”, “*How do you ...?*” (following Harper, 2012a; Lofland et al., 2006, and Spradley, 1979). I asked what was ‘going on’ in the photographs, so that interviewees might speak about their own experiences and feelings (and see Brand & McMurray, 2009, pp. 32-33). For the participant-generated images, I asked what they had intended (Mannay, 2010, p. 100), as well as whether there were images they had been unable to take for any reason (Harper, 2012a).

Process—photo-elicitation

Publicly accessible images of care/support work and workers were collected (Harper, 2012a; Rose, 2001; Sproule, 2006) from locally available state and national newspapers, as well as from an online image source, google images. Terms for the google images search were “disability”, “disabled”, “aged”, “old”, “aged care/r”, “aged care work/er”, “support work/er”, “disability care/r”, “disability care work/er”, and “disability support work/er”. The final portfolio comprised 72 images. Photographs (with their captions) were cut out of newspapers or brochures or printed (in colour) from the online source and laminated. The source was identified on the reverse (see Appendix F).

I used these photographs as prompts in the second long interview with people in the worker group. I did not ask participants to respond to particular images or to all the images; rather the interviewees commented on any that interested them.

The reflective researcher: Fieldnotes, transcribing and reflection

The first day you'll see more than you'll ever see again. And you'll see things that you won't see again. So, the first day you should take notes all the time. (Goffman, 1989, p. 130)

I began a fieldwork notebook (there were eventually 3) on the first day of recruiting and made entries for observations and formal or informal interviews. I also dictated audio notes and reflections (an example of an audio note is provided at Appendix J). After leaving each interaction, I think about how it had gone, what had been said and done and the roles and performances of the various actors, including myself. I was attentive to the strange, the “that’s funny”, and my own position and reactions. I noted what I shared with participants, and what set us apart, and how I and they were performing. I tried to record my suppositions and prejudices, as well as my “value commitments and [...] the effects of [my] work” (Hammersley & Atkinson, 2007, p. 14). I also

kept a project diary, recording day-to-day events, reflections sparked by transcribing and summaries of and responses to literature.

Several times, reflections sparked shifts in my practice, analysis or interpretation. One example was a reflection that occurred as I was driving to interview a participant. I caught myself thinking, *"I wonder if [X] has fallen in love with me yet?"*. This thought appeared, almost signpost-like, and I stopped the car. I knew that I did not want the participants to love me in any romantic way, but love seemed to be the right word for what was needed.²³ It alerted me to the trust and disclosure needed if interviews were to work. It made me wonder about the manipulative aspects of the research relationship and reminded me to pay attention to my own candour, friendliness and relationships with participants. I talked with my secondary supervisor,²⁴ and read or re-read literature about interviewing (Birch & Miller, 2000; Cain, 2012; Eide, 2008; Ezzy, 2010; J. Hewitt, 2007; Horvath & Luborsky, 1993; Shaw, 2011; Spradley, 1979; Travers, 2006). My own role and performance needed to be honest, candid and attentive to the emotional impact of the research relationship and the embodied emotional performance aspects of interviewing (Ezzy, 2010).

The complexities of listening became apparent. The first few times I had difficulty understanding what someone said, I felt perturbed, tried to work it out, but let the conversation continue. Then, during early observations, I noticed that some of the support workers seemed not to worry if they misunderstood or did not properly hear what a client was saying to them. When I reflected on this, I realised that not making sure that I understood what people were saying to me was dismissive of their contribution. I adjusted my

²³ This was an inkling of what became an important notion in the data. I return to it in Chapter 8.

²⁴ I am also grateful to Jack and Noel for their insights into the idea of the therapeutic alliance in psychology.

practice. I paid closer attention to what was said and, if I did not understand it, said so (e.g., “I’m sorry, x. I didn’t understand that—would you mind saying it again?”).

It was sometimes hard to hear everyone in the few group interview situations. Some people were noisy and gregarious, and others reflective and thoughtful. Although these were a small minority of interviews, I tried to ensure that everyone was ‘heard’ and to watch for changes in participants’ manner. In an interview with Brian and Miriam, he suddenly became quiet. He and Miriam had been talking about responding to the diverse cultural needs of residents in a facility they had worked in. Brian made a provocative remark about a particular culture and, shocked out of my intended neutrality, I probed him about the statement. Transcribing the interview made the shift in the interview dynamic apparent: “[Miriam seems now to be talking more, not stopping when Brian interrupts ... or he may be pulling back; I slightly wonder whether he detected my discomfort about the [particular] culture discussion”. This was a reminder to suppress my automatic reactions to things that disturbed me. Transcribing was also invaluable for alerting me to the need to keep the goal in mind (Hammersley & Atkinson, 2007, p. 118), to be clear and succinct, and to be quiet and “create a space” for interviewees to think (Silverman, 1989, p. 219).

Reflecting on observations drew my attention to the many occasions when participants ‘played to the gallery’ (me) or attempted to use me as a sort of validator or side-kick. One person, for example, made several witty and sarcastic asides to me about the worker. Another person showed me a book in which she listed items she was teaching the support worker. In both cases, the clients seemed to be inviting my approval or tacit siding with them. These displays, and my growing awareness that I was the audience for this very particular performance, signalled a key shift in my analysis—I became aware of the necessity of performing the competent self:

There is a sort of dance going on between me and the participants; they are performing for me when we are in the interview, and they perform as well in the observation. But they also perform for one another ... (Fieldnotes)

I mention this phenomenon here, and focus on it in later chapters.

Table 3.3. Interview, observation and other data

Worker	Client	Worker interviews	Workers' other data	Dyad Observation	Dyad photo-voice images	Clients' other data	Client interviews
Dyad partners	Anita	3	10 emails; 1 reflection	3	?		3
	Blanche	3	Txts	2	19	1 reflection; copy of diary	6
	Brian	4	4 documents	1			2
	Edwina	2	Txts; 1 reflection	2	—	3 reflections	3
	Joanna	3	Txts; 1 reflection	1	89	1 reflection	6
	Leonie	2	2 reflections	—	—	2 reflections	2
	Sharon and Justin	1		1		2 reflections	1
	Shirley	2	Txts	1	—	1 reflection	2
	Stella	2	Txts	1	—	2 informal conversations; 2 (unrelated) reflections	3
Clients	Cornelia						2
	Norah						2
Workers	Jai	2	3 informal conversations				
	Lilla	3					
	Miriam	2	1 informal conversation				
	Ruby	2					
	Tash	3	Txts				
	Tilda	3	Txts; 1 reflection				
	Vic	4	1 reflection				
		41	32	12	108	15	33

* Images taken but cameras not recovered

Fieldnotes were written for every interview and observation, and mostly incorporated into the start of transcripts as contextualising material. Informal

material was not used as data; it informed interviews as prompts or discussion topics.

Interpreting the data

Data analysis

Table 3.3 details the data gathered during this research. Data analysis was shaped by the research question and sub-questions:

How do practice and meanings of care intersect in the delivery of support to people with disability and the frail aged?

How does practice shape meaning?

How do clients shape practice and meaning?

How are the work, the worker and the recipient depicted in public documents?

Data was analysed thematically, following an iterative process. Three overarching themes guided data gathering and analysis. They were: Presentation of self, Performance, and How participants talk about one another. From this beginning, the cycles of data gathering, reflection, analysis and new data gathering re-shaped how I understood the themes, in the light of developing sub-themes. I read and re-read all material, categorising excerpts, passages and events into groups that reflected the four basic topics of interest: self, other, meaning and action. Thematic categorising initially took the form of highlighting and labelling passages (using the reviewing tool in Word) with the broad, predetermined themes, tentatively described emerging themes, and questions raised by the material and reflections. As data gathering and analysis continued and I re-read transcripts, clearer themes were highlighted and further questions flagged. Both the themes and the questions prompted additional reading from the literature. As well as exploring literature on the researcher-participant relationship, I read about depression and self-care for

care and support workers, sexuality, body work, touch, and meanings of home. I also ‘tried out’ emerging themes—stripped of the speaker’s identity—with all participants, including via the photo prompts (Appendix F) and short reports (Appendix H), to ‘test’ categories and gain clarity and depth (see Hansen, 2001). Participants offered incisive perspectives on the emerging themes, and on other participants (including via the unexpected links between them) (see Figure 3.4). This series of steps was repeated several times.

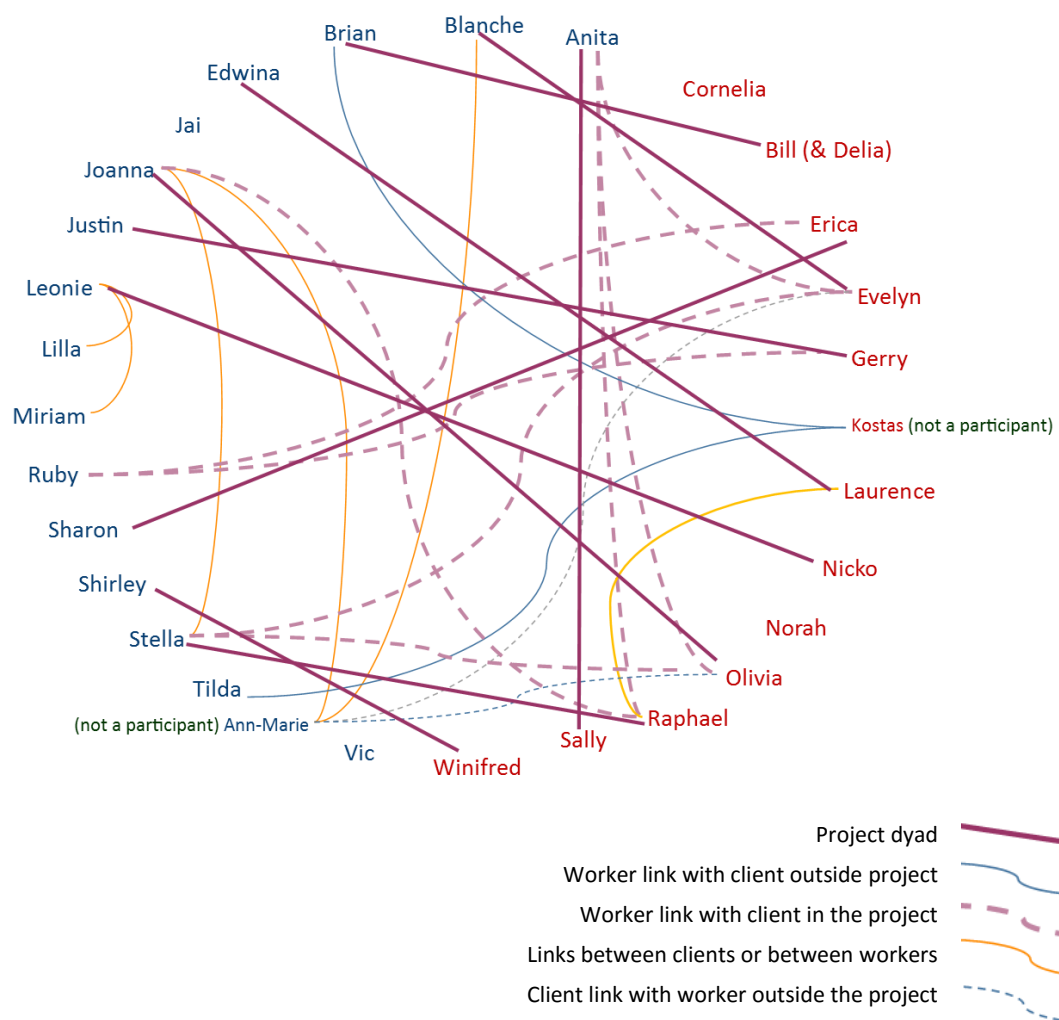


Figure 3.4. Formal connections and informal triangulations

There were several, unforeseen, opportunities in the study to gain additional perspectives on individuals and interactions. Some workers visited several

client participants, and some clients had several worker participants visit. I heard about Kostas, for example, from both Tilda and Brian; about Stella from Raphael and Evelyn; about Raphael from Anita, Stella and Blanche; and about Olivia from Joanna, Blanche and Anita. These webs of perspectives provided a kind of triangulation. Tilda and Brian described Kostas quite similarly, yet their responses were quite different, and Raphael's view of Stella was, for all his cutting wit, more kindly than Evelyn's. These over-lapping perspectives and reports were particularly useful when considering both the observed and reported interactions.

Methodological and theoretical notes

The notes I made reflected both upon what I did and on the participants' reactions and outcomes (as far as could be discerned) (Schatzman & Strauss, 1973, quoted in Newbury, 2001, p. 5 of 17), as well as on method, methodology, and theoretical perspectives. I was looking for meaning in what I had seen and heard; this was where thoughts and conceptualisations started to meld (see Hammersley & Atkinson, 2007). I drew maps of what I thought was happening, trying to tease out and then show how the themes and the other factors uncovered in the data gathering were connected, and how they acted upon one another (Newbury, 2001).

There were many confrontations with "feelings of personal comfort, anxiety, surprise, shock, or revulsion" (Hammersley & Atkinson, 2007, p. 151). They often signalled a clash between my understanding of my role and the challenges of the actual experience, or between my expectations and what the data were revealing. I kept in mind Travers's description of the task as "an attempt to respect reality [...] as it is experienced and understood by ordinary members of society, going about their day-to-day business in the everyday world" (1997, p. xii). Points of discomfort sparked shifts to new ways of seeing and a more fitting way of thinking.

In search of meaning in the data

Goffman's work on interaction and the dramaturgical analogy, as well as the broader theoretical approach of symbolic interactionism shaped how I analysed the data. I was looking for evidence of how the workers and clients constructed and reconstructed self in the "pattern of verbal and non-verbal acts by which [the actor] expresses his view of the situation and through this his evaluation of the participants, *especially* himself" (Goffman, 1967, p. 5) (emphasis added). In Goffman's conceptualisation, actors (try to) manage social encounters, roles, and relations in order to present the self, create particular impressions and avoid stigma. For both worker and client, body has "an important role in mediating the relationship between people's self-identity and their social identity" (Shilling, 2003, p. 73) and is therefore central to performance. Further, there are costs in failures to perform according to the script of "competent and worthwhile human being" (Shilling, 2003, p. 75). Identity can be 'spoiled' and embarrassment and stigma come into play.

Clients risk a spoiled identity (Goffman, 1963b) through public constructions, disabling circumstances, and incapacity or limitation; incontinence is an example, as are dribbling and other signs of the absence of control (spasms, or postural, or verbal outbursts, or speech impediments). But workers too may be unable to meet expectations of social, physical or intellectual competencies; examples include literacy or ways of behaving that demonstrate particular social status. In order to counter such risks, the participants in support and care work may engage in tact or diplomacy to save face for others (Goffman, 1967, p. 12). There are avoidance and defensive measures as well as protective strategies in face-to-face interaction. Thus, "almost all acts involving others are modified, prescriptively or proscriptively, by considerations of face" (Goffman, 1967, p. 13).

Each interaction is dense with meanings: gestures and postures, touches and their absence, facial expressions and gaze, pretence and tact, and the words that are offered. These elements create a tightly woven engagement in which all those interacting are working on their own and the other's 'face', making decisions about whether to be with, to be above, or to defect. Thus, in analysis I was attentive to presentation of self (theme 1), and to workers' and clients' performance or practice (theme 2). I also paid attention to how the actors talked about their opposite number—the person they interacted with and with whom they created meaning and enabled or disabled presentation of self (theme 3). Finally, I was alert to how the participants described their interactions and relationship, and to what my observations revealed about this face-to-face performance (theme 4).

Conclusions

Repeated interviews, conversations and observations were used to expose workers' and clients' rich performances and presentations of self, half-hidden beneath frontstage, surface acting. I was shown at least some of the deeper backstage selves. Goffman's theatrical analogy and ethnographic methods gave me a backstage pass to the world of support work. In analysis, I followed Spradley's advice and tried to make "maximum use of the native language" (1979, p. 24). A symbolic interactionist perspective enabled the exploration and representation of "the meanings encoded in that language as closely as possible" (Spradley, 1979, p. 24).

The next chapter, Chapter 4, forms a bridge between the exposition of methodology and methods and the reporting of thematic analysis. In Chapter 4, the actors, the stages upon which they perform, and the street views of the play are introduced. Then, in the subsequent three chapters, the results are reported in terms of the major themes of 'Presentation of self', 'Performance', and 'How

participants spoke about one another', first for workers (Chapter 5), then for clients (Chapter 6). In the final results chapter (Chapter 7) the relationships between clients and workers—both reported and observed—are described.

Chapter 4.

Findings: Setting the scene—Introducing the workers, the clients and where the work happens

This is a study of the intersection of care and meaning in the practice of support. Care and support involve often intimate practices aimed at maintaining public performances of capacity and competence. Preparations are made backstage for effective frontstage performances. Backstage is also where performance can fail, and where stigmatisation, exploitation and demeaning can flourish. These characteristics also make the backstage subject to public speculation about vulnerable clients being ministered to by low-status, poorly trained and sometimes cruel workers. Most often, though, the 200,000 strong army of Australians working to provide ‘hands-on’ assistance to people of all ages who have disabilities are out of sight and out of mind, their experiences and motivations unexamined.

This chapter builds on the far-view from the research literature and the political and workforce discussion in Chapter 2. I firstly explore how this sector and its players are constructed in the discourses about care and support active in the study’s geographical setting. Then, moving to a still closer view, I describe the study’s location in the southern region of Tasmania, before introducing the participants and places where support happens.

Depictions of aged care and disability support

Every day, all over the world, the media network replaces reality with lies. Not, in the first place, political or ideological lies (they come later), but visual, substantial lies about what human and natural life is actually made of. All the lies converge into one colossal falsehood: the supposition that life itself is a commodity and that those who can afford to buy it are, by definition, those who deserve it.

John Berger, *The Shape of a Pocket*, 2002, p. 202

Gathering the stories

In May 2014, the Australian federal Treasurer Joe Hockey handed down his first budget. Focusing on prosperity and how to maintain it, his key theme was that such prosperity would flow “if we all contribute now”.²⁵ His speech ended with reference to two sorts of Australian: the ‘lifters’ and the ‘leaners’. This was a familiar sorting: both in Australia and elsewhere, the ‘leaners’ — recipients of unemployment, aged and disability allowances — are regularly ‘clamped down on’, while the ‘lifters’ are valorised as worthy citizens. I wondered what such a framing might mean to those people who receive overt welfare payments²⁶ — including people on pensions or allowances related to disability — and how such messages might affect the way others treat them. My impression that aged care and disability support were stigmatised in public discourse had been a driver for the present study, but was that impression accurate? How were the work and its participants represented in public media?

Over the period of the study, I gathered stories from the local print media as well as a national online news source. My aim was to remain aware of what

²⁵ The transcript of the speech is available at < <http://www.smh.com.au/business/federal-budget/federal-budget-2014--full-speech-20140513-3887i.html> >.

²⁶ There are multiple ways in which ‘lifters’ also receive government support.

these parts of the community were saying and how aged care and disability support were discussed. I performed a simple descriptive review at the end of May 2015. The scope was far from comprehensive and the findings thus only broadly indicative.

The media sources were relatively conservative: southern Tasmania's one local newspaper, *The Mercury*, one readily available national newspaper, *The Australian*, and a Melbourne newspaper, *The Age*.²⁷ The national online news source I checked was the Australian Broadcasting Corporation's news site <<http://www.abc.net.au/news/>>. When stories about aged care and disability support drew my attention, I collected them (see Appendix K). I read the headlines, liftout quotes and photograph captions (if any), and then asked two people—not connected with the project—to record their impressions of the same material, as marginal notes beside the excerpts.

Seventy-two stories were gathered between February 2012 and May 2015. The readers' marginal notes fell into categories of how actors (workers and people with disabilities) or places of work were represented and how aging or disability policies were discussed. Three themes were identified: political risk, institutional and personal risk, and the 'othering' of workers and clients.

While it cannot be assumed to represent the public discourse as a whole, the review revealed clear skeins of depiction. The first is of aged care and disability support as politically and economically risky; neither the right of recipients to high quality support nor the importance of the work were assumed. The second theme is that aged care and disability support are sites of personal risk: people who work in the sector may be caring, but more often are portrayed as inadequately trained, care-less or cruel. Finally, people with disabilities were

²⁷ *The Age* is published by Fairfax; its Sydney counterpart, *The Sydney Morning Herald* often publishes the same material and was sometimes accessed. Both *The Mercury* and *The Australian* are published by News Corp Australia and News Corp.

presented as 'others' who lack agency. Things are done to them and they respond with gratitude or hope.

Newspaper content: Themes of political and economic risk

At the end of 2011, a major national wage case recommended that community sector support workers receive a wage increase. This was touted as signalling increasing gender equity and was approved in 2012.²⁸ In this period (before formal news gathering began), there were stories that highlighted how the wage rise would address the relatively poor pay that care and support workers receive. These were good news stories, often depicting celebrating workers, though some stories that described workers as deserving also implied that they had gained at the expense of taxpayers (Killick, 2011) and overall prosperity. Killick's story (2011) had the headline "Pay battle jackpot", suggesting that there was something undeserved in the decision. These themes continued throughout the story gathering period.

The wage-case headlines from February 2012 onwards were seen by the three readers as mostly positive. We noted that the gender equity aspect of the pay increase was described as a good thing [articles 2, 9, 27, Appendix K]. But the pay rise was also seen as being portrayed as a "win" [2] that workers had landed, like a fish that hadn't gotten away [1]. There was an implication that it was not deserved. Readers also noted the suggestion of risk [3, 4, 6, 8] with descriptors like "hike" [6] accompanying warnings of flow on claims and

²⁸ Two provisos are relevant to the gender equity argument. Firstly, many home-care support workers are not covered by the SACS award. They received no increase other than that flowing from wage indexation. Secondly, workers in day centres (who are covered by SACS), are at the lower levels of the awarded increase (between 19 and 30%). Increases of over 30% generally apply to office staff in provider organisations where female workers make up a smaller proportion. The effect of this is that, while the wage decision of 2011–2012 was celebrated as a major step towards equalising pay between the genders, the part of the aged care and disability support workforce overwhelmingly made up of women received either the lowest percentage wage increase (19% over 8 years) or no increase (see Hussein, Ismail, & Manthorpe, 2014, for a discussion of roles occupied by men in long-term care).

dangers to the economy. The wage rise would hurt the budget bottom line, and be “exploited” in rolling wage claims from ‘greedy’ unions [3, 4, 5, 8].

Two more national changes received considerable attention in the media. In 2012, an insurance scheme to fund disability supports was proposed by the Commonwealth Government and the first trial of the scheme was established in Tasmania in July 2013, with trials in other states following. The National Disability Insurance Scheme (briefly called Disability Care) was portrayed as promising a new independence for clients [13, 14, 25, 41, 46]. This coincided with the announcement of a shift to a client-directed model in aged care [20, 30, 35]. Support for both changes was tempered by concerns about how they would be paid for [26, 32] and claims that they were grandiose schemes aimed at immortalising the prime minister [33] or fundamentally changing the relationship between the states and the Commonwealth [15]. These stories constructed aged care and disability support as sites of political and economic risk.

Newspaper content: Themes of institutional and personal risk

The second theme was that of crisis, risk and threat [10, 12, 16, 17, 48, 70, 71, 72]. The headline “Australia not equipped to cope with growing ‘tsunami’ of dementia cases, advocates warn” [71] encapsulated the theme of demographic threat. Stories flagged the rapid growth in demand for disability and aged care support workers in response to an ageing population, as well as the need for more and better trained care and support workers [10, 12, 18, 21, 42, 53] and costs to the economy [15, 22, 26, 38, 39, 43].

Linked with demographic threat was the personal threat posed by workers and institutions. Workers were portrayed as the perpetrators of neglect or cruelty [19, 29, 44, 54, 62] and facilities as places of condoned abuse [45, 47, 49, 53, 57, 58, 63, 64, 65, 68, 69]. Over the period of the study, abuse or cruelty stories

surfaced, rash-like, every few months. Among the most alarming are a story comparing aged care facilities unfavourably with concentration camps [49], and articles reporting indignities, abuses, assaults and deaths [19, 29, 44, 45, 54, 62, 68] in disability support and aged care. The images accompanying these stories are of torsos marked with welts and bruises or of angry-looking family members. In all but two [54, 62] of these headlines, no distinction was made between staff at the different levels; it was simply that people being supported were at risk. On the other hand, only two stories were seen as portraying workers in a positive way, linking them with caring [21, 40] as a virtuous and meaningful activity.

Newspaper content: Themes of the passive, difficult and homogenous other

Risk stories—indeed almost all stories about people with disabilities—portrayed a vulnerable and powerless other. The exception was a story about the long ADE²⁹ work record of a Tasmanian man [66]. Otherwise, people were constructed as flat and homogeneous entities—the “disabled”, “elderly and disabled”, “frail” [10, 14, 21, 22, 24, 25, 57, 58, 59, 63, 66, 68]—who were teary [23], hard work [7] or bewildered [18], presented a problem for their “exhausted” families [31, 36, 37] or the nation, and needed protection [58], and “dignity” [16, 17]. Dignity and capacity were not things they were automatically assumed to have. Even when the headline referred to a positive event, the stories rarely presented participants as having individual agency or power. Where individual stories were told, people with disabilities were

²⁹ Australian Disability Enterprises (ADE) were formerly known as sheltered workshops, a title derived from their intended role as workplaces that ‘sheltered’ people from competing on the open employment market. They operate as commercial businesses, and people with disabilities earn an allowance for their work. The allowance is significantly less than the work would attract outside a disability enterprise, a fact that is the subject of a continuing debate. For more on this see the Australian Disability Enterprises website <<http://www.ade.org.au/news/10-employers-fear-disability-wage-reform-will-cost-jobs>>, and People with Disabilities Australia <<http://www.pwd.org.au/campaigns/real-wages-for-real-work.html>>.

presented as exemplars of struggles or as passive and ‘victims’ [15, 17, 18, 23, 28, 29, 36, 49, 54, 62, 67, 68] of insensitive or cruel systems and individuals. Alongside these were a small number of stories which my readers marked as depicting people with disabilities as ‘leaners’. In much the same way that the wage increase for support workers had sometimes been depicted as a lucky ‘win’, payments and supports to people with disabilities were portrayed as something from the ‘lolly jar’ — a bonus or gift rather than as a right [16, 55, 56, 60, 61]. Terms like “crackdown” and “welfare cop” were used in connection with policing the Disability Support Pension.

The two-dimensional portrayals of workers and of people with disabilities in these news stories shed little light on real lives or experiences of support and care. These constructions are consistent with other researchers’ more precise and controlled examinations of media portrayals of disabled and elderly people (see, for example, Dahl, 1993; Fealy et al., 2012; Gardner & Radel, 1978; Gold & Auslander, 1999b; Markstrom, Sjostrom, & Ljuslinder, 2011; Rozanova, 2006; Rozanova et al., 2010; Rozanova et al., 2006; Shakespeare, 1997). This literature showed that people with disabilities are frequently portrayed in flat, homogeneous categories. For older people this may be as healthy–engaged or decrepit–disengaged; for younger people, as pity-worthy–heroic or demonic–erratic. People with disabilities are frequently essentialised in media as *all* being other, objects of the public gaze. The depictions reported here are consistent with those in the earlier studies.

How aged care and disability support are discussed and described matters, since social identities are constructed and sustained in conversations and interactions, and in discursive contexts like public media (Haller & Ralph, 2001; Rozanova et al., 2006; Shakespeare, 1997; Sontag, 1990). Thus, how the participants in aged care and disability support view one another, and how

they understand themselves to be viewed, is likely to shape their practices and relationships.

In the next section, the focus narrows to the study's location in southern Tasmania.

Southern Tasmania

[There were] all these [hospital] wings [closed] off, and all locked doors [...] I'd sit there and I could see some traffic going by, and I used to think, "People driving by ..." —It's the first time I'd even known about [it] [...] "People driving by don't know that there's people living like this, you know, locked up, and demented, and ..." stuff like that. (Blanche, works in community)

Blanche, a participant in this study, had learned of the hidden world of patients and inmates and workers when her father had been hospitalised with dementia, in an old-fashioned mental hospital. That hospital still stands, but in common with such facilities throughout Australia, it is now part of a modern aged care facility, albeit with its own locked wards for people with dementia.

Participants in this study work and live in southern Tasmania and its capital city, Hobart. Tasmania is Australia's southern-most and smallest state, making up just less than ten per cent of the country's total land mass,³⁰ but with only two per cent of its population. Whereas on the 'mainland' the population is clustered in major cities and towns along the coast, more than half of Tasmania's 514,000 people lives outside Hobart (Department of Premier and Cabinet, n.d.). It is also the State with the highest proportion of older people; the median age of the Tasmanian population in 2012 was 40.8 years [<http://www.abs.gov.au/ausstats/abs@.nsf/Products/3235.0~2012~Main+Features~Main+Features?OpenDocument#PARALINK5>], compared with the national

³⁰ <<http://www.ga.gov.au/education/geoscience-basics/dimensions/area-of-australia-states-and-territories.html>>

median of 37.3, and the 'ageing' of Tasmania's population is more rapid than in other states (Australian Bureau of Statistics, 2012b). Ageing is associated with increasing levels of impairment (National Centre for Social and Economic Modelling (NATSEM), 2004): almost a fifth of older Tasmanians had a profound or severe disability, but younger Tasmanians too have higher rates of disability than the national average (Australian Bureau of Statistics, 2013a). Tasmania was the first trial site for the National Disability Insurance Scheme, with a pilot project for people aged between 15 and 24 years implemented in July 2013. These characteristics mean that there is a significant and growing need for services which support people with disabilities—perhaps particularly in Tasmania. The next section introduces the study participants, workers and clients in aged care and disability support.

The actors—and the theatres

Workers

Seventeen of the participants worked in the community, in day centres and group houses or facilities. I gathered some demographic information about them during the preliminary interview, and by later readings of their own and other participants' interview transcripts. Worker participants ranged in age from 26 to 68. Eleven were older than the national average age for care and support workers (>47). Four men took part (24%; the national rate is closer to 15%); three of them were less than 40 years old. I did not ask whether participants had a partner or spouse, or whether they had children, but most of the women talked about their children during our conversations, as did one man. He also told me during our first meeting that he was married, but for others participants this information came out incidentally or not at all.

At the start of the study, seven people were working exclusively with younger people with disabilities and one person (working in the community) was

working with both younger and older people with disabilities. Twelve of the fifteen participants who reported their support work history had worked in residential aged care. Four remained working in residential aged care, two worked in residential disability facilities and six had moved into community care or support work.

They had varied pre-support work employment histories. At least two had had executive roles in private enterprises, some had experience at various levels in the hospitality industry (as wait-staff, and in front of house), and two had run small businesses. Their reasons for moving into care and support work varied, but often they spoke of being drawn to it because of particular experiences; some were eminently pragmatic—aged care in particular was seen as a growth industry. Only four had never worked in another industry.

The youngest participant also had the highest qualifications—a Certificate IV in Disability and a Certificate IV in Aged Care. Two other people were completing nursing training, one to become an enrolled nurse (EN), and the other a registered nurse (RN). Both qualified during the later part of the study. These three were all men. Two women had started and left uncompleted undergraduate degrees. Every participant had at least a Certificate II and most had a Certificate III qualification.

Seven workers were recruited directly and ten joined the study after being invited by a client. The seven in the first group are Jai, Lilla, Miriam, Ruby, Tash, Tilda and Vic. The ten workers who were recruited as part of a client:worker dyad are Anita, Blanche, Brian, Edwina, Joanna, Justin, Leonie, Sharon, Shirley and Stella.

Sharon and Justin were interviewed just once; they changed roles soon after we talked. In contrast, I had several conversations with Anita, Leonie, Vic and Brian. Some of these conversations were formal and audiorecorded and some were more casual; in all cases, I made written or spoken notes (using my digital

recorder) when I returned to my car, or got off the phone. Anita and I had several email ‘conversations’, and Leonie and I met and corresponded. I did not directly use any of the material generated in these correspondences, but sometimes they informed a later formal interview with that person.

Workers not in research dyads

Jai, Lilla, Miriam, Ruby, Tash, Tilda and Vic had come to support work along various paths and worked in several different settings.

Jai—worker

Jai was working on a higher qualification that would take him out of support work. He had had several jobs, most involving health in one way or another, and had come to support work for pragmatic reasons: it was a reliable means of earning a steady income. He had worked in several nursing homes, as well as some hospitals with aged care respite beds. He said he was happiest about the place he worked at now, focusing on people with dementia. Jai was inquisitive, intelligent, robust, iconoclastic and a little combative in our two formal and several informal conversations.

Lilla—worker

Lilla, Jai and Miriam had all spent most of their support work history working with people with dementia in residential facilities. Lilla was matter-of-fact and laughed a lot. We met for three interviews as well as having a couple of informal conversations over coffee. Her history was full of care and support roles, she’d had a childhood wish to be a nurse, and she had recently moved away from hands-on work to a part-time administrative role in a health organisation. She had also taken on a different sort of support role, this time involving children.

Miriam—worker

Miriam was at the point of retiring from aged care work, having worked in several nursing homes over 40 years. As the study progressed, I discovered that she had worked with at least three other participants who mentioned her as an exemplar of ‘the good support worker’; they looked up to her. Miriam was mild and quiet; mostly she listened and offered perspectives rather than confidently asserting expertise. We met three times.

Ruby—worker

Discomfort with her experiences in a residential facility for disabled people had, in part, pushed Ruby into her present role in a disability day centre. She had spent almost three years in direct client support, some of that as a support worker and some as a key worker, running programs for a small group of people with disabilities. When we met, she had responsibility for a much larger number of programs for people with intellectual disability. Ruby’s job was permanent and full time. She had a Certificate III in Disability and started another qualification towards the end of the study.

She was quite careful in our two long conversations, only sometimes seeming to relax.

Tash—worker

Tash was an old-hand, with many years of experience in disability support and aged care work under her belt. She now worked for a disability services provider, in both a residential facility and with community clients. She worked for around 45 hours a week, some at the weekend (she commented that without weekend penalty rates she would be unable ‘to make ends meet’). Tash had started support work when qualifications were unusual and not required and had gradually earned a Certificate III. That early work had been with people with very severe disabilities and it had involved a lot of practices which were

both ineffective and cruel (and have since been banned). Her connection with disabled people, though, was even longer; as a child she had sometimes accompanied her aunt to work in a nursing home and had interacted with disabled people in a recreational activity. Further, she had moved in and out of volunteer roles in dementia units. Tash was straightforward, clear, confident, and had a “*really warm, knowing and observant-seeming*” smile (Fieldnotes). She was also very candid about where she worked. Tash and I met three times.

Tilda—worker

Tilda divided her time evenly between shifts in a residential facility and shifts in the community. She had been working in aged care—and almost always full-time—since she left school aged about 16. Now, she was close to retirement age. Tilda had not intended to become a care worker; she had wanted to nurse overseas. Personal events had interrupted her plans. Tilda had strong connections to a religious community, and its culture and her role in it was a strong thread in our conversations. Of all the participants, Tilda was the only one who expressed concern about confidentiality. As well as her work experiences of aged care, she had family experiences of both aged care and disability support, only some of which were positive. In notes after our first meeting, I described her as “*warm, seeking, opinionated, strong, sad, angry ... she feels undervalued as a carer*”. Tilda and I spoke three times.

Vic—worker

Vic was enthusiastic and career-oriented. He was working in two jobs and had been for some years. In his support work career he had changed employer organisation several times, seeking more hours or better positions. When we met, most of his work took place in a residential disability support facility, but he had also worked in community disability and aged care work, in a group house and in a residential aged care facility. In his support work roles, Vic

worked six shifts each week (two of them double shifts). For one shift he supported a community client to attend a social activity outside the facility. Including his other job, Vic was working well over 40 hours a week.

Vic's manner was shy but candid and sincere. When the conversation turned to sad or emotionally fraught topics, he almost whispered and he chose his words slowly and carefully and sometimes stumbled over them. When on surer ground, the hesitation disappeared and his voice was louder and had a happy edge. When I asked him why he had wanted to be part of the study, his immediate response was that he wanted the voices of younger men in support work to be included. He was quietly confident about his ability and emotionally engaged with his work (as will be shown in Chapters 5 and 7).

I interviewed Vic four times. When I met him for the fourth interview, he had just resigned from the facility and was working in a very different, and more senior, service sector role.

Clients

Workers told me about houses and facilities they had worked in. Some were physically unpleasant; dirty or cramped. While such places certainly gained attention in the media reports reviewed above—as places of at least benign neglect and sometimes of overt cruelty—none of the clients in the study lived in such conditions.

As I started recruiting participants, I visited as many 'theatres' of work—residential facilities, group houses and day centres—as I could. From my outsider (Spradley, 1979) observations, the residential facilities varied a great deal. There were modern, high-ceilinged ones, with nicely laid out gardens outside, soft carpet and original art inside, and only the faintest scent of disinfectant on the air. There were new-wave, efficient and low-key ones, with various pets, gardens tended by the people who lived there, and fix-your-own

coffee and tea stations that residents actually used. And there were shabby, smelly and noisy ones, reeking of institutionalisation and suppressed anger. Sometimes on these visits, people who lived or worked there might come past, and they too varied. In the manicured, aloof places, residents were out of sight, ensconced in their spacious suites, and staff were polite, quietly efficient and benignly smiling. In the shabby and smelly, the staff were loud, and domineering. They congregated in the tea room and responded to the residents' bell-calls with shrugs or smirks. The residents looked bewildered.

The status, appearance and fees of residential facilities, though, are not necessarily indicative of their being 'good' places to live. I visited many that were pleasant, and a couple that weren't, and received all sorts of welcomes.

The welcomes at day centres and group houses were universally warm, and the staff and clients appeared integrated, so much so that sometimes I wasn't sure who was which. Day centres had a cheerful, fairly home-like bustle about them, with people doing things, whether it was helping to make morning tea, arrange activities, or sort out bus timetables or football tipping competitions. People talked. In the group houses, there were few hints of any differences from other shared houses.

These visitor's views of places and people were superficial. I learnt more from workers about the places they worked in, sometimes in grisly detail. But seeing the inside only happened when residents or community clients consented to be part of the project. Then, I was invited into the rooms in residential facilities, group and private houses. I interviewed people in these places, and observed work being done.

Clients not in research dyads

Cornelia and Norah did not recruit workers to the project.

Cornelia

Cornelia led a fairly independent life and received the least support of any client in the study; she had domestic assistance one day each fortnight (though other assistance was on call). She had never married and had pragmatically moved into an independent living unit (ILU) more or less on retirement from her academic role. She had continued to travel overseas until the last couple of years. Cornelia's unit was neatly laid out, the carpets were thick and soft; there were several bookshelves, and artworks on the walls. The quest for a low-risk environment, though, had built in what Cornelia called "*silly*"³¹ design. There was a red alarm button on the wall, about which she was critical, saying that it wasn't much use if she'd fallen elsewhere in the house. Cornelia had been a professional and was used to things working, to having effective systems in place and responsive staff, and to being taken seriously.

She told me about some musculo-skeletal problems she was being treated for and the changes they had required in how she did things. She also had a much richer relationship with the support worker coordinator for Crescent than she reported having with workers themselves.

Norah

Norah had access to more or less constant support. She lived in the low-care part of Cliveden, a well-appointed residential facility, having moved there when her mobility declined. Her room was full of light and there were some personal things (artworks and small pieces of furniture) here and there. Norah could come and go as she wanted, and the place was close to shops and a park. The external doors had coded key-pads; only those who could remember the

³¹ Excerpts from the data are in italics. Excerpts from the literature or other sources are in Roman script.

code could come and go. Cliveden was clearly comfortable, and she was friendly with several other residents, having known them before she moved in. Norah and Cornelia's places reflected their financial success. Norah and her late husband had been professionals, and she had a no-nonsense, warm manner. Although living in the residential facility was practical, she disliked the frequent changes of staff. She wondered whether the worker she invited to join her in a research dyad had declined due to concerns that her participation would be discovered by the facility managers.

The ten clients and their worker dyad partners are introduced in the next section, where the nature of the support is also detailed.

People in research dyads

Client and support worker demographics

The twelve clients in the study included the oldest and youngest participants (92 and 21). Seven were women. One was married, two had been widowed, and one divorced. Only ten clients were part of a research dyad. As was the case for workers, the amount of contact I had with dyad participants also varied. I had many interviews and informal conversations, and in some cases email or letter correspondence, with Olivia, Evelyn, Laurence and Raphael, but met Erica and Gerry only once.

Winifred—client, and Shirley—worker

At 92, Winifred was the oldest person in the project. Winifred was delicate:

She's very small—she would come up to my shoulders maybe. Um, very thin.

Perfectly turned out, however. Beautifully dressed; carefully dressed. Her hair nice.

Um, a sort of a perfect little granny, in a way. Sorry! Ah, and a generous person.

So, there wasn't any grabbing, or grasping, or "I want ..." or "I need ...".

(Fieldnotes)

Winifred was widowed and lived alone. While not strictly an ILU, her place was linked to a large residential aged care facility, where her husband had lived for some time before he died. At 92, Winifred was not able to use the front steps to get in and out of the house, but the back doors opened (at level) onto a small, flower-filled courtyard. There were fresh flowers in the house each time I visited, and a sense of reliable calm amongst possessions that were good quality and well looked after. At the centre of her living room stood her wing-back chair and a carefully equipped rolling table. She called this her *"control centre"*. Pulled up close to her chair, its drawers held ledgers and calculators, measuring tapes, lozenges and Band-Aids. A glass of water and other books rested on the top. Here, she could *"still do all my own accounts, and money [...] I'd ask [my son] something about business, and he'd say, "Mum, you know more about that than I do"*.

Winifred had been *"having radiotherapy which has made her quite tired, and that distresses her. But she's a cup half full kind of person"* (Fieldnotes). When we first talked, the radiotherapy meant that she was not well enough to be interviewed; she called me some months later, and was now able to take part. Her interest in the project was driven partly by the gratitude she felt for her support workers (*"my girls"*, she called them), and partly by an interest in social policy and politics. She had been receiving support for more than 12 years, sometimes at quite high levels; her EACH package now provided 13 or 14 hours each week. The workers did, *"Well, just about everything for me now. Yes. They do my shopping. They do a bit of cleaning. They help me with my cooking, and ah, yes, just general everything, I suppose..."*.

Shirley was one of Winifred's *"girls"*. She formerly *"came occasionally, but, ah, only the last two years she has been coming regularly"* (Winifred). Counter to the

way recruitment of workers in the dyads was intended to happen, I met Shirley first:

Just had a call from a nervous sounding lady: Shirley. She had been at the ECA meeting at Many Hands last week (Thursday) and felt that—even though she was “not one for standing up” and talking, and didn’t feel she was very good at expressing things, she said “if you don’t hear from us you don’t get the true picture” [...] She also said she had talked about the project to one of her clients (a lady “with all her marbles”) and that she had not asked the lady to be part of the study—but the lady had asked her if this was something that could be good. She also said the client was very interested in aged care and policy. (Fieldnotes)

Shirley and I met in a café, chosen by her because it was an accessible one where she often took clients. She was, as she had warned me, nervous and spoke very quietly at first, becoming less tentative as the interview progressed. Shirley had been working for Many Hands for 14 years, starting without formal qualifications. She described this as being “*thrown in the deep end*” (Fieldnotes). She had since completed a Certificate III in Aged Care.

Shirley was employed on a permanent part-time basis. She worked 56 hours each fortnight, and this included working one weekend a month (both days). When we first met, she had eight clients most weeks and saw some of them three or four times a week. They were mostly people she had worked with for a long time, the longest for nine years. Winifred is not the oldest; one person she visits is 97. Some of those she sees have dementia and some have memory loss. Shirley’s week was typical for the community care and support workers in this study. Most mornings, her first appointment was at 7:15, and she left home at 6:30 to arrive on time. The shortest visit was a 10-minute medication prompt or “*just checking in*”. Other visits were for showering clients and helping them to dress. Shirley did the washing up, made beds, did laundry, and prepared meals. Some of the clients she was with while they ate, but she did not ‘feed’

any.³² Sometimes she took clients out, did shopping for people, or took them shopping. The longest session was two or more hours for in-home respite (she stayed with the client while their caregiver went out).

Shirley's longest working day ended at close to six o'clock in the evening, and the shortest in the early afternoon. Like most community-based workers, she had holiday and sick pay and was not paid for lunch times. She did not get public holidays but tended to take leave on those days. On public holidays, services are reduced to personal care, medication prompts and meal preparation; that is, the things that are essential.

Olivia—client, and Joanna—worker

Olivia emailed me, and we met at a café. She was a surprise: she had told me some basic information about herself and the reasons she received support, but none of her impairments was apparent when we met. She was robust, capable, forthright, warm, and adventurous. Her walking stick leant against the table. On our walk back to her place, she flourished the stick, rather than leaning on it.

Olivia's place was a very small semi-detached house, for which she expressed great gratitude. Its size required her (and support workers) to be orderly. There were compact gardens, front and back, a very small kitchen and a living room wedged in between bedroom, bathroom, kitchen and entry. Olivia had an elderly dog, Elijah, who slept in the living room and took walks with support workers, or with Olivia. Mementos of Olivia's life were everywhere in the house: as well as family photos, there was art that linked her with the political and cultural life of her homeland. Under the window, she had a large table

³² 'Feeding' and 'toileting' are controversial terms in aged care and disability support, which are widely used but also regarded as demeaning. They are discussed further in Chapter 5.

ready for her creative projects; this was the only apparently disordered part of the house—it was piled with papers, books and pencils. A desk just inside the door held only her computer and the telephone; reminiscent of Winifred’s ‘control centre, this was Olivia’s “communications centre”.

Olivia was in receipt of a CACP, totalling no more than three or four hours a week. “Two workers visit—one who mainly does domestic assistance (cleaning and so forth), and the other [Joanna] with whom she goes shopping and for coffee and so forth—social support, she called it” (Fieldnotes). Olivia’s interesting life was gradually revealed to me over many conversations.

When I met Joanna, she was in the last few weeks of her role with Hillcrest. She had come to support work a couple of years earlier, after a very successful career in which she had a great deal of responsibility. Looking for something new, and less stressful, she “went into aged care ... because I knew I would be guaranteed I’d have a job, always” (Fieldnotes). She worked about 25 hours each week, visiting people across the region. She had worked for a very short time at a residential facility and had been “so horrified” by what she saw that she would not go back into residential work.

Raphael—client, and Stella—worker

Raphael called me on a Sunday afternoon to tell me he was interested in being part of the project. He had seen the flier in a pile of things from his provider organisation and had asked a couple of the workers who visited him about it. One of these, Stella, told him she was already in the project and she and Raphael had talked about it. With that connection established, we arranged to meet the following week. Stella told me that he liked good coffee and newspapers. I arrived armed with a copy of *The Age* and a coffee from a nearby café. Raphael’s place was in an old-fashioned block of flats, built in the grounds of a crumbling mansion. I knocked and Raphael called out for me to come in.

The place was a little dark. He, too, had a sort of control centre, with books, radio and CDs, and a cup of coffee close to his armchair by the window. There were books and documents and a couple of pieces of equipment for a hobby he had on the dining table. In common with Olivia's place, there was, to an outsider, a slight sense of disorder about parts of the house, and it did not have the clinical starkness I saw elsewhere.

Raphael had someone visit morning and evening, six days a week. They "help" him to get out of bed, to shower and dress. They prepare meals, and do the laundry and house cleaning. He had a worker go with him to do his shopping, and some social support each week. Several further people dropped in—a worker came to oversee his medication, and people delivered prescription drugs (in Webster packs).³³

Stella was one of Raphael's support workers, visiting him twice a week to do some cleaning and laundry. Originally trained in nursing, Stella had worked in aged care for some years. She was in early middle-age and was working two or three days a week. One of these days was a Sunday, for which she was, she said, very well paid. She seemed to be fairly senior amongst the workers in her organisation, with access to rosters and the ear of some in management.

Evelyn—client, and Blanche—worker

I met Evelyn after she called me, sounding "very straightforward and clear" (Fieldnotes). I met Evelyn at the door of her unit, one of a string of buildings off a busy road:

So, I went through the entrance hall, the small but very tidy kitchen and into the lounge. Opposite the door is a window with a very nice view out across to the bay

³³ A Webster pack is a medication management tool prepared by pharmacists. It is a plastic sheet of multiple day-and-time-labelled pouches containing the tablets or capsules prescribed to be taken at a particular time and particular day.

[...] I commented on it and she pointed out bits of the landscape. At a small table near the window was a piece of craftwork under construction. (Fieldnotes)

Evelyn's history was present everywhere, in family photos, paintings and tidy bookcases. Things were in their place, and that mattered to her. Evelyn, too, had been a professional. She was used to structuring her life, and kept documents and notes in a filing cabinet. After a couple of visits she showed me the file she had started about me and the project; she put notes she had made about her experiences of support work, as well as newsletters from the provider organisation in the folder to show me when I next visited.

Evelyn was open and candid, and lived a life of the mind. She was interested in social research and in this research in particular. As well as her career, she had a history of volunteering. But perhaps her central interest now was her very elderly and unwell dog, André, who spent much of his time asleep on her bed, and was prone to vomiting.

Evelyn's experience of support workers was only fairly recent, beginning after a serious illness had left her unable to take care of her daily activities. This illness was the latest of a number of physical challenges she had experienced. She credited her recovery and independence to her high-level (up to 20 hours each week) EACH support package. Three or four workers visited, performing more or less the same set of tasks. Blanche is one of the workers. She:

comes on a Monday for support—they call it personal support, or something. She'll do dishes, make beds, um, if I want to wash my hair—I'm still not au fait with washing hair [...] Then she comes on Thursday, comes in the morning for personal support then two hours in the afternoon for cleaning. [...] Or if I do need shopping, [...] then an hour on Saturdays and about an hour on a Sunday.

One day a week, Evelyn had what she called "a holiday". No one came that day, largely because there were no workers she liked available. I met Evelyn's dyad partner, Blanche, at Evelyn's place.

Blanche was in her 40s, and was neatly and practically dressed. She told me that support work was not her original role, but that her partner's career-directed moves between a number of cities in other states had left her without work. She had wondered:

"... what can I do?" And I always wanted to do this sort of work, 'cause I visited my dad in that place—... And so I thought, "Oh, I'd love to do that". So I saw it in the paper, a training course, and so I did it! And that was, oh, I'd say about ten years ago or something, then.

Blanche qualified as an assistant in nursing and after several more moves came to Tasmania where she worked for a short time in a residential aged care facility before finding sufficient work in community care, again focused on aged care. Getting enough hours remained difficult; although she worked five days a week, the work on those days was not constant, and there were sometimes large gaps between rostered visits.

Blanche did all the things Shirley had listed, and also mentioned evening routines, when *"we just do everything in reverse! Give them something to eat, get them into their pyjamas, put their electric blanket on, brush their, clean their dentures, you know—any, whatever they need [...] Take their dog for a walk"*.

Sally—client, and Anita—worker

Sally's pets played a central role in her day, chiefly her kitten Olaf. She was *"criticised by one friend for having him [...] Yes, 'cause I'm old and in a wheelchair"*, and Olaf did expend a lot of energy bounding or clawing his way onto and off her knees. Olaf needed to be let in and out of the French doors to Sally's garden, and discouraged from shredding the furniture. Since Sally used a wheelchair and had the slightly limited use of only one side of her body, chasing after Olaf occupied a lot of her attention. Sally also had a small elderly dog, who seemed to take care of herself, though Sally sometimes tied her lead to her wheelchair and they went to the end of the street and back; the dog was exhausted by it.

Sally's rented place was set among other similar accessible units in a quiet street. It was compact, a little shabby but quite well laid out. The kitchen was tiny. Sally, too, had a sort of control centre—a table near the middle of the large living room, with her computer, a water glass and some pill bottles on it. From here, she watched television, used her computer, and could see her productive vegetable garden.

Sally had been a health professional and was realistic about her own failing health. A stroke had resulted in a loss of function on one side of her body and her need for a wheelchair, and she had other serious conditions which were further reducing her physical capacity. On my first visit, a community nurse arrived to change a dressing on an infected wound that had been healing extremely slowly. Sally also complained of severe pain in the hand on which she relied to maintain independence—to eat with, to operate her chair, to assist with her own bathing and using the toilet, and to use her computer and phone.

Workers visited Sally every day, providing personal care and doing the cleaning and laundry; the total was 15 hours each week. She and a worker also spent one afternoon each week preparing meals which were then frozen for use over the following week. Sally was very interested in food and cooking. On the day I first visited her, Sally was working out her menu for the coming week, and talked about whether she and the worker, Anita, would have time to prepare the dishes.

Anita had been working with Sally for three years and as a support worker for five. An injury had ended her previous role:

I had a, an accident. Um, so I couldn't go back to the work. I just wouldn't have coped with it at that time. Probably couldn't now, actually. So I had to decide

“What do you want to do?” And it was either animals or old people, because I felt really comfortable around both.

She had completed a Certificate III and spent a practicum in an aged care facility, an experience that left her *“absolutely mortified. [...] I went home in tears for the first two nights, and I just thought, ‘This can’t be happening!’”* (Anita). Now, Anita worked only in the community, with older people and some younger people with disabilities. She worked six days each week (the most hours of anyone in the study), but had had several periods of leave recently and so was unclear how many hours she might do in future. Anita also did quite a lot of out-of-hours visiting and checking in with clients; it was not always easy to tell which hours she was rostered for and which she was doing unpaid.

Laurence—client, and Edwina—worker

Laurence had already been suggested as a possible participant by another participant, who described him as *“amazing”* and a *“very high achiever”*. When I met Laurence at a day centre where he went at least once a week, he asked me about the project and took a flier. Later that day he texted me to say he was definitely interested, and we set a time for what was the first of three formal interviews and several informal conversations. He was extremely enthusiastic about the project, and research in general. He had a long history of working in volunteer roles for provider organisations and was something of an activist. Laurence was tall, thin, and intelligent. I had seen how he engaged with others at the day centre, which was noticeably polite and interested—and solicitous; he seemed to be a central and invigorating presence. He was also the youngest person there.

Laurence lived alone, and had for some years. His place was pleasant yet stark. As well as the lack of clutter—clutter would have prevented him from moving about the house freely in his wheelchair—there were few pictures on the walls and little in the way of personal objects. He told me how depressing he found

this starkness (it diminished after he changed providers). Despite being purpose-built, there were some small things which disabled him about the place, including three long steps up to the front door. The paved slopes outside felt precariously angled, too. But it was quite close to shops that he was able to get to on his own.

Support workers visited at least twice a day. He was very unhappy with the service provider; when we first met, up to 13 different workers were rostered to work with him each week. He, and the worker he invited to take part in the study, Edwina, both moved to another organisation shortly after we met.

Edwina too had an activist streak. She lived a somewhat unconventional life and was vocal about possibilities rather than limitations. Edwina had worked with people with disabilities since leaving school, sometimes in residential facilities and more recently in the community. When Laurence invited her to take part in the project, she was also delivering aged care support in the community and had been working with Laurence for about a year. I first met Edwina when she arrived at Laurence's house to start work. She was warm, if a little brusque, and greeted Laurence with a hug and an armful of groceries. Laurence's description of her as: *"it's like having a big sister or a mother"* visiting rang true. She was bustly but attentive.

Nicko—client, and Leonie—worker

Nicko and the support group he was part of had a money-free arrangement. As a young man, Nicko had sustained a brain injury which had left him unable to walk and with memory problems. When the money for his treatment and rehabilitation ran out, *"They wanted to put me in an old people's home"*. In rehabilitation, though, Nicko had met Leonie who was visiting another person. They struck up a friendship and she met some of his other friends. When the threat of being placed in aged care loomed, the nascent friendship group

decided to take other steps; Nicko moved in with Leonie. Nicko, Leonie and the others have worked on his rehabilitation steadily, so that he now lives in his own place.

Nicko's house was probably a response to the financial imperative of squeezing several compact living spaces onto a piece of flat land. Despite the constraints it was:

actually much more 'his place' than some of the others I've been to. Lots of pictures and objects connected with things he has a passion for and of people and places... Everything was ordered and clean, and his fridge had loads of greens in the vegetable crisper. It was a good set up. (Fieldnotes)

He proudly showed me one room that was filled with tools and mementos of his former occupation and which housed his gym equipment. He also had some reminders here and there—a large diary, as well as some pinned up notes—to jog his unreliable memory.

The only paid support he had when we met was with cooking. The support group were protective of one another, being *“very careful to ensure that ‘Nicko’s not, sort of exploited, or treated like a victim’ [she said]. Or that he was talked about with that [as Leonie put it] ‘Oh gosh—isn’t this impressive, isn’t he marvellous’ kind of perspective”* (Fieldnotes).

When her *“previous life of being married, having children, running a business [...] all fell apart”*, Leonie *“needed a job to earn money; that I didn’t have to think about”*.

Through a friend she started work as a *“cleaner, laundry person, kitchen person, whatever they wanted”*, in a small nursing home. The work appealed to her. She went to TAFE to get some qualifications, and moved to a much larger facility. By the time she met Nicko, she was working mostly with people with dementia. That work continued alongside that of the support group, and she expanded her training role, moving away from hands-on care and support. At the time of the study, she was working full time. Her interactions with Nicko now almost

never included physical support; managing social connections and volunteer work remained an important role for them both.

Bill—client, and Brian—worker

Bill was in his late eighties—and full of stories from his interesting and long life. He'd had support for "*Oh, I dunno—bloody years*" since a stroke and other illnesses had changed his physical capacity. Bill and Delia lived in the house where they had brought up their children. It was large, more or less the stereotypical brick and tile house of the 1970s, with picture windows and busy carpet, and had a wide sunny garden. The main room had comfortable-looking sofas, a big dining table and a couple of 'nests', for the small dogs who were mostly pleasantly ignored. Bill and Delia spent a lot of time indoors, chairs drawn up to the table with its tin of biscuits, 'chewing the fat' and drinking cups of tea made by Delia. There were papers and pamphlets from a variety of community organisations and sporting clubs at one end of the table. The slight disorder of life in a big family still permeated the place, though Bill and Delia's children were now well into middle age.

Delia prided herself on being Bill's carer, though she herself had a dementia diagnosis. Support workers were in the house most days, helping Bill to shower and dress, doing some cleaning for them both, and providing social support and respite. Bill also had regular visits from a community nurse, who checked his blood pressure and general health.

Bill told me that his dyad partner, Brian, was straightforward, a view Brian echoed, saying, "*I don't put on airs and graces*". Brian had been an executive with: "*my own office, my own secretary, three-piece suit, you know, car parking space*" but the job had moved inter-state and he had not followed it. Instead, he had trained in aged care and had been working as a "*carer*" for 13 years, some of

those in a dementia-specific unit³⁴ and some in the community. Brian saw a range of community clients now, some with dementia, some simply a bit frail, and some younger people who experienced bouts of mental illness. For Bill, his role was social support, though he sometimes helped around the house. Brian was working on a higher qualification which would take him away from support work. In the meantime, he worked the equivalent of a five-day week.

Erica and Gerry—clients, and Sharon and Justin—workers

Erica and Gerry shared a group house with five others, including two workers who slept over. They had been house mates for almost a year.

The house looked like its neighbours, and was large: *“there are enough bedrooms for each person to have a room—as well as a kitchen-dining area, a large lounge room, a kind of study area (which has gym equipment in it) [...] The housemates have a lorikeet”* (Fieldnotes). Other than the size of the bathroom (enormous) and the presence of a shower chair and some rails, the house was like hundreds of others in middle Australia: spacious, with expanses of tiled floors in the kitchen and dining room, inoffensive carpets elsewhere, a big-screen television and a cage to which the bird sometimes returned.

I think I arrived not thinking of the house as just another share house, where people’s rooms were their flats, more or less. But that is how it is—Erica’s room is absolutely her space [...] And Gerry’s room is that of a footy fan with a penchant for a particular pop star. (Fieldnotes)

I was invited in by Erica’s key worker, Sharon. We went into the kitchen, where another worker, Justin, was preparing a meal. Erica, Gerry, Sharon and I sat at the large dining table, while Justin kept working in the kitchen. The other people in the house came and went. Erica was talkative, reflective and warm; she liked living in the group house: *“I like to be around people!”*. She was the

³⁴ Several different terms are used for dementia units. I use the term ‘dementia-specific unit’ for facilities (or parts of facilities) that residents may not leave unaccompanied.

youngest person in the study, and attended a training college each week and had paid cooking work with a 'disability enterprise' (ADE). She had recently learned to catch the bus to work. Living in a group house for her held familiar joys and trials: she liked the company, but disliked the chores of keeping the place tidy. The members of the household shared the cooking and cleaning, and were involved in planning menus and doing the shopping. She described herself and Gerry as *"actually the really good ones — most of the time"* in terms of doing the housework. But, she felt restricted by the presence of the other housemates and wanted to live in her own unit.

Gerry had been living in the house longer than Erica and is a few years older. He too went out to work, doing agricultural jobs in an ADE two days a week. On the other weekdays, he did sporting and other recreational activities through a day centre. Gerry talked about several social events and adventure activities as well as about the recreational opportunities he had while living in the group house. His key-worker was only sometimes at the house.

Sharon and Justin, as Erica described it, *"Look after us. They just here to talk to us, and look after us. To see if anything hap, if something happens and stuff like that. 'Cept we do the work most of the time"*. When I asked Gerry what he and Erica called Sharon and Justin — whether it was workers, or just "Sharon" and "Justin", he replied, with a laugh, "Workers!", and rubbed his hands together with satisfaction. As Erica's key-worker, Sharon spent part of most days with Erica, and had responsibility for planning and for working with Erica on new skills. Key-workers, as Sharon said, are *"there just for you. So if you need anything, we've got to organise it. If you want to go on a holiday, we organise it with you"*. Sharon was in her early forties and had some experience in aged care, and in other disability support work. She had not been a key-worker before. Justin was a key-worker for a person living in another house, but was doing support

work in Gerry and Erica's house on the day we met. Justin was taking time away from university studies and was in his mid-twenties.

Sharon and Justin both took a back seat during our interview, letting Erica and Gerry talk and only commenting now and then to add their perspectives about particular aspects of their work. These four people were the least involved participants in the project, due to their work and other circumstances.

As the project continued, and I visited people more than once, observing work and the interactions between the players, more details about the settings appeared. These rooms reflected and shaped both the lives and the work of those that used them.

Conclusions

So far, the focus of this thesis has narrowed from research reported in the academic literature and in policy and demographic studies to the current media discourse. In all those perspectives, care and support work may be invisible or framed in terms of organisational concerns like turnover and training, or use the language of burden, oppression, inadequacies and stigma. The people involved—clients and workers—appear most often as object other; the workers because of their low status and 'poor' education or their role as agents of oppression, the clients because of their distance from some ideal being whose bodily leaks and erratics are managed and secret. The voices of care and support workers in particular are almost entirely absent. Moving closer still, the setting for the present exploration of the work in southern Tasmania (and some of the associated risks) was described and the participants in the study and the places where that work takes place were introduced. From here, the participants take centre (back)stage as they perform and rework the scripts and choreography of aged care and disability support.

Interview, observation and photo-voice data analysis was shaped by the research question and its sub-questions:

How do practice and meanings of care intersect in the delivery of support to people with disability and the frail aged?

How does practice shape meaning?

How do clients shape practice and meaning?

How are the work, the worker and the recipient depicted in public documents?

In analysis, three overarching themes were central. They were: Presentation of self, Performance, and How participants talk about one another. In the next two chapters, Chapters 5 and 6, results in these overarching themes are reported, first for workers and then for clients. Chapter 7 then delves into the construction of meaning in the relationships between workers and clients (the fourth major analysis theme: Co-constructing meaning). This is where emergent themes in the data—about the enabling and disabling ways that participants interacted—come to the fore, revealing the significant co-construction roles played by both clients and workers in the presentation of self and the maintenance of face *for both workers and clients*.

Chapter 5.

Findings: Working to deliver care and support

Ten years ago, if you'd have said to me, "Jeez, Brian, I reckon you'd make a good carer", I'd have said, "Pig's arse! I'm not touching the old people! And as for wiping someone's backside ..." But, coming home and knowing you made a tangible difference in someone's life—I helped a lady die today: I held her hand.
(Brian. Works in the community)

Introduction

Brian's first response to aged care work is congruent with the negative discourses evident in the last chapter. 'Old people' were other, to be avoided, and intimate body work was impossible to contemplate. Yet Brian had shifted from disgust to what sounded like a sort of love. His remarks went to the heart of the project's guiding question of how care and meaning intersect for workers delivering services to people with disabilities, and how recipients shape practice and meaning.

I interviewed Brian and most of the other sixteen workers in the study at least twice and some, three or four times. I also sat in corners, lifting my feet as vacuum cleaners whirled by, or trailed workers and clients as they went about the activities and conversations of service encounters in kitchens, lounge-rooms and bedrooms, day centres, cars, and shops. These data revealed how the workers saw themselves as well as other ways in which they expressed their self-evaluations. Here, and in how they talked about their role (the practice), they described themselves as caring and compassionate. Watching them work, and listening to their comments about themselves, work and workers, revealed

that care was about sustaining the competent performance of clients and residents. It was also clear that workers' ability to perform and sustain clients was affected by their emotion work and agency, and by the practices, policies and rules of the organisations for which they worked. These external, structural, forces shaped workers' capacity to act; policies, rules and imposed practices determined the extent to which workers were 'the authors of their acts' (Benjamin, 1988), limiting their self-efficacy. The successful support of clients and residents, moreover, was an important part of workers' own presentation as competent and caring. They worked for the mutual presentation of selves that were internally congruent and capable.

Three overarching themes guided data gathering and analysis: Presentation of self, Performance, and How participants talk about one another. All three drew on the evidence in the "pattern of verbal and non-verbal acts" workers used to express their "view of the situation and through this [their] evaluation of the participants, *especially [themselves]*" (Goffman, 1967, p. 5) (emphasis added). Further, this self is, "diffusely located in the glow of events in the encounter and becomes manifest only when these events are read and interpreted for the appraisals expressed in them" (p. 7). Thus, the work is also shaped by the recipients; the ways in which the participants talked about clients concludes the chapter.

In Chapter 6, the presentation of clients, their performance and how they talk about workers and organisations is reported, before Chapter 7 brings the two groups together and describes their interactions.

Theme 1. Workers' presentation of self

Workers were seeking to present an "internally consistent" face, one that was "supported by judgments and evidence conveyed by other participants, and

that is confirmed by evidence conveyed through impersonal agencies in the situation” (Goffman 1967, pp. 6–7).

The picture painted in media stories of aged and disability care and support as a sometimes savage place (see Chapter 4) is not easy to dismiss. Workers themselves spoke about clients who were erratic, loud, aggressive and scary, and about family members who were domineering. Perhaps partly to counter these realities, and the negative public discourses about care work, participant workers did a great deal of impression management (Goffman, 1967), taking care to present themselves as caring, compassionate and nurturing people and to explain that good carers require a combination of personal qualities and experience.. This took two forms: 1) workers stated their own qualities, and 2) compared their performance with delinquent or incapable others. When I asked each person to tell me about themselves and their reasons for becoming a care or support worker, their responses had a common, though not universal, theme of ‘being a caring person’. When they spoke about other workers, their often highly critical remarks provided a richer picture of the work, and boosted their own presentations of competence. Further, when the inappropriate practices of other workers were ignored by management (or perpetrated by them), the interviewees felt disheartened and pessimistic. Administrators, managers and medical practitioners were found wanting. In all these presentations and comparisons, there was a sense that some of the workers felt either under scrutiny or under threat, and that they had little power or influence. They were, nonetheless, establishing an impression of power and capacity that was experiential, and presenting care as a practical phenomenon, something both developed and displayed in work.

Care and support workers presenting a compassionate self

All workers engaged in impression management, presenting a compassionate self. They described themselves as making a difference and as bringing

something particular to their work. Most spoke of wanting to make things better for clients, and of the satisfaction or joy that brought. For some, their choice of care and support work was portrayed as almost vocational; others presented selves that were practical and pragmatic.

About half the workers seemed to feel especially qualified: care and support work was their vocation. Miriam was quiet about her own capacities, but she had a sense that 'good carers' belonged to a *"different breed"*. This echoed Ruby's discovery that *"I was in my element and nothing else kind of mattered"* when she started support work. The sense of vocation was also present in remarks made by Lilla, Tilda, Edwina and Shirley. Lilla and Tilda had *"always thought"* they would become nurses. Tilda had always wanted to *"look after"* people. This group also argued that the necessary traits were either innate or learned very early in life. Lilla had the example of her grandmother — *"an amazingly caring person; she was just phenomenal. Um, nothing was a drama to her. [...] I learned a lot from her"*. Such role models had given Lilla a *"yardstick for me to measure by"*. Workers' own illnesses or traumas — and the resulting experiences of care — provided another yardstick, playing *"a huge part"* for Lilla and three others.

The other distinct group of workers — Jai, Vic, Joanna, Leonie, Brian and Anita — had come to the role later and chosen support work pragmatically (Christensen, 2010). Anita and Joanna both told me (while laughing) that, finding themselves in need of work, they had tossed up whether to work with old people or animals. They recognised the growing need for aged care and disability support workers and that this was long-term, stable work. Vocation and sentimentality were absent. They had taken a *"job to earn money; that I didn't have to think about"* (Leonie), and because *"I knew I would be guaranteed I'd have a job, always"* (Joanna). Vic had weighed up his skills: he was not *"great with my hands, or I'm not really good with numbers or anything, so I thought what am I really good at? And I thought, well, I'm a compassionate person, caring and tolerant — things like that"*.

Their pragmatism was coupled with “*a great respect*” (Joanna, Jai) for older people.

The ‘pragmatic’ workers appeared to be united in having a solid sense of their own worth and professionalism. They were also rebellious. Each gave examples of having ‘battles’ with other staff, or management, sparked by poor practice. For Joanna, “*There’s a right way and there’s a wrong way*”, but being prepared to confront poor practice and “*stupid, stupid protocols*” (Tash), made them feel like outsiders. All members of this group presented ethical selves that stood up against bullying or demeaning practices, and expressed their frustration with the sector.

These rebellious workers were also reflexive. They told of experiences that had driven them to adjust their performance in an effort to make interactions successful. Anita, for example, reflected on how she worked, often remarking that “*there could have been a better way to handle that*”. Such reflexivity was part of what Brian called “*authenticity*”. Being “*real*” mattered: “*Timeframes are for people that are scared of contact or scared of being real [...] if I miss out on a fifteen-minute break because I’m holding somebody’s hand because they’re a bit upset, you know — no loss to me*”.

All 17 workers in the study, though, had a shared project to present themselves as compassionate people. Most told me stories that illustrated their deft touch with clients, and that demonstrated their attention to detail and the seriousness with which they took their work. These autobiographical presentations were enhanced by stories that described how other care and support workers performed.

Workers’ identity by comparison

Workers’ conversations with me were littered with discussion of other workers’ practice—how *they* lacked the people skills to manage situations, how *their*

training had left them with ‘on-paper’ knowledge but little of practical use, that *they* were lazy or incompetent, or seemed to have missed out on essential adult knowledge and lacked wisdom. Untrustworthy, cruel or abusive others were also described. Sometimes, participants were complimentary of another person and, by inference, themselves or they reported sticking up for colleagues in ways that reflected well on the speaker. All this was impression management to counter the largely negative social constructions of care and support work and workers.

When Vic used comparison he was complimentary. He told me Sharon, a fellow worker, who was *“sixty [...] and she’s overweight, so. And she goes flat out like I do”*. More often, comparisons were two-edged. Tilda—who was frequently critical of people she worked with—made some supportive remarks about fellow workers. Of her *bête noire*, Sarah, she said: *“She’s really good at that. And I commended her for that, last week [...] she’s probably even more perceptive than I am in those sort of situations”* (emphasis added). A proviso, *“at times”* diluted the praise.

Education and experience (explicit and tacit knowledge) were often seen as competing assets. Joanna, Leonie, Vic and Ruby, who had higher or more recent qualifications than most others, regarded the fact that organisations employed under-qualified people as *“a bit of a slap in the face to the people who’ve studied before coming in here”* (Vic). For others, long experience replaced the education status shield (Hochschild, 2012), putting them *“on an equal standing with other professionals”* (Edwina). Many in this latter category echoed Brian’s view that *“you can’t learn dementia, from a book”*. They felt their ‘hands on’ knowledge was too often disregarded.

Some workers claimed a particular sort of ‘hands on’ knowledge. They talked about a category of clients or residents whom other workers had described as difficult, or had refused to work with, because they were viewed as abusive,

uncooperative, or just challenging. The workers' own success in such interactions was a source of pride. The subtext in these comparisons was that the speaker had worked some magic—been a kind of 'client-whisperer'. Miriam gave examples of being able to work with residents who were experiencing significant trauma and who were sometimes aggressive. *"We had one man, and no-one could do him, and I used to shower him of an evening when I'd come on. He was just sweet for me [...] had a wonderful relationship with him"*. Shirley had *"two clients that a lot of the other girls won't go to"*, and Blanche talked about a person who was *"hard work"* and whom *"so many support workers would refuse to go back to"*. But, when Blanche visited, *"she loved me—and I loved her"*. Blanche described this person as being pleasant one minute, and then *"the nastiest, nastiest person the next"*. Brian had calmed a *"distraught"* resident: he *"held both her hands softly, held both her hands on her lap, and talked to her"*. Workers said that their interventions frequently created a particular bond with that person.³⁵

Workers were also critical of peers whom clients disliked or who were lazy. There were workers who earned a *"lot more than me, but yet I'm better than [them]"* (Joanna), who left client incontinence for others to manage, left beds half made and treated people's possessions with disrespect. *"Some of them just don't have common sense, or something"* (Shirley), and some were simply not up to the work: *"There's a lot of workers who aren't physically strong enough ... They can't even lift, can't take a jumper off a guy"* (Vic). Blanche—and several others—talked about a particular worker: *"so many people hate Ann-Marie"*, *"so many people won't have her"*. Sometimes, such critiques were about instances where others' lack of attention was *"likely to trigger [...] You know, that sort of stuff that's actually going to make that behaviour escalation worse"* (Ruby).

³⁵ The work of Steven Sabat on the role of implicit memory for people with dementia is informative here (see Sabat, 2005, 2006).

Tilda took the opportunity presented by one of the photo prompts (Appendix F) to talk about another worker's "*bad habits*" and several people reported their responses to perpetrators of poor practice or outright bad behaviour:

I just looked at her and I said—in some really colourful language—"You are so lucky I did not sit you on your arse there. Do not ever do that to a resident while I'm working with you ever again, 'cause you will not get up". (Lilla)

Like other workers in the study, Lilla went on to reinforce her own good motives, saying that the worker "*went off saying to the other carers, you know, what a bitch I was and blah, blah, blah—for caring*".

Stella was critical of workers who were "*a bit rough*", and cruelty was roundly condemned. Some was verbal cruelty, like the sorts of conversations Miriam and Brian reported overhearing when residents clamoured to 'go home'. Other workers might respond: "'No. You're here'. *I've heard them say it. 'This is where you live. You're here. You're not going home'*" (Miriam). Several (Miriam, Lilla, and Anita among them) gave examples of witnessing other workers humiliating residents:

"Come on, you've pissed yourself!"

"Get in here you old bitch! Now!"

"For fuck's sake! [shouted] I come in here an hour ago and you wanted to pooh.

And you didn't do anything—are you sure you want to do it now?"

Physical abuse was also reported by Leonie, Joanna, Miriam, Jai, Brian and Anita. They had caught workers "*slapping a resident*" (Miriam, Tilda, Brian, Jai), or force-feeding people (Joanna, Lilla, Brian). Other abuse was by neglect. Early in her aged care experience, Leonie:

went into the guy's room to put his laundry away, and there were blow flies all around him, and I just lost it. I just thought, 'My god, how awful'. Like this should not be happening. [...] I went, raced down to the matron's office and I said, 'So-and-so's up in his room. There's blow flies all around him, he's stuck on his

commode, no staff around, rah, rah, rah'. And she just ripped strips off me...

'You're making too much out of it. And it's a hot day and what do you expect?'

Finally, Anita, Tilda, Brian, Tash, Jai, Miriam and Lilla all gave examples of colleagues' failure to deal appropriately with clients' or residents' emotions. Tilda stressed that *"you've also got to be mindful, like if you start asking questions like that, that you don't leave people raw"*. She underlined her own competence when she added that *"not everybody would be aware of that sort of thing"*. Brian spelled out what several others seemed to be suggesting, putting the distinction between his own practice and others' bluntly: *"It's about [...] being better than the bloke next door that says, 'She's a fucken idiot; she needs putting away'. You know?"* They used care as a yardstick. *"It just frustrates me that, ah, it's not that nobody knows anymore, it's that nobody cares [rising inflection]"* (Brian).

These stories are important signals of unacceptable practices—a frequent topic in media (see Chapter 4)—in care and support settings. The stories also positioned the participant workers as both better workers than others and as advocates for residents.

Summary

Workers presented themselves as compassionate and competent, both through autobiographical remarks, and through comparisons that distanced them from others who were less competent, or even cruel. While only a few workers admitted to being intimidated by the environment in which they worked, all made it clear that they could have been and that others were. Some participants claimed to be better equipped than others for the work required.

Theme 2. Workers' performance

Practice is where care and meaning intersect for workers delivering services to people with disabilities and frail older people. Workers were enthusiastic reporters of the work they did; within those descriptions, their presentation of

self as compassionate and competent continued. The support tasks, described in Chapter 2, are intended to assist clients with the ‘instrumental activities of daily living’. Tasks seldom occurred in isolation from one another. Rather, it was clear from the analysis that they coalesced in workers’ overarching task of supporting clients’ presentation of intact and competent selves. Their efforts in two broad areas—grooming and meals—are exemplars described below.

An additional element of practice was also apparent: emotion work. Workers tried to manage their own emotions in order to complete tasks that might be emotionally difficult. They also worked to create the “proper state of mind” (Hochschild, 2003b, p. 7) in clients such that support was accepted and the physical tasks could be performed. This was particularly striking when workers faced ‘difficult’ clients (whom we heard about in the ‘client-whisperer’ material above), when they were confronted with physical and emotional risk, and when they dealt with grief. Workers may be more or less equipped (physically, emotionally) for the work, and the work is shaped by organisational policies and behaviours.

“Supporting people in their everyday lives”³⁶

Practice involved physical busy-ness, as workers tried to complete their tasks within short time-frames. During observations, they were in constant motion. Watching Anita working with Sally, I wrote in my notebook that “*Anita just keeps getting on with the work. There is no stopping or resting*”. Everyone I observed stopped only when the client spoke too quietly to easily hear, or when they were called over to look at or comment on something.

Tash worked in a disability residential facility. Her description of her mornings was typical for workers in facilities:

³⁶ Ruby.

I turn up at quarter to six [...] on a Friday morning, so I can have a cuppa and a ciggie before, before I start—[...] then we go round and knock on all their doors, of those that aren't awake [at] quarter past six [...] then we go round and then there's some that shower in the mornings, um, so we make sure that they're in the shower, have got clean towels, and go round, shave them, make sure all the women are dressed properly, hair's done. And then get them out to breakfast.

Tilda described facility work as “it's [makes chopping gesture], you know, like twenty showers one after the other. And then, and then wheeling people out to the dining room or whatever”. Facility workers' days would then continue much as Ruby described for her group house role:

supporting them to sort of get ready for their day, um, and depending on the level of their ability, you know, maybe there's more support [...] and then the transport [...] Weekends would just be, you know sort of, just be dependent on what everybody wanted to do [lilt], um, but there would be certain weekends where you would have to go and do the shopping, and you know, that sort of stuff, but it was always with the clients, yeah, supporting them with social outings as well. [...] It's just supporting people in their everyday lives.

There was greater variety in community work, which was usually a mixture of some shopping, medical or social trips with clients, short visits, long respite sessions, or interactions for personal care, cleaning, cooking and laundry. The shortest visits—to prompt the client to take medication or check to see how they were—were around ten minutes in duration. In community work, many workers felt they could be a sort of helpful friend:

So, I guess, we're not someone coming to do something for you, but someone coming to visit you, and we can do this while we're here. That's how it would be—

that's how I would like it to be, when I eventually have to have someone like me come. (Anita)

(Re)Creating the competent performance—presentation of clients' self

In performing their tasks, experienced workers were trying to 'recreate' an ordinary life. Tasks like vacuuming, cleaning bathrooms or kitchens, and doing the laundry maintained the physical environment for clients or residents. Clients, residents, family members and others could thus experience the frontstage settings of houses or rooms as familiar and looked after. But the clients' own presentation and performance occupied more of workers' effort. Two groups of tasks where clients' and residents' presentation of self could most obviously succeed or fail are personal presentation and food-related tasks.

Personal presentation

Grooming tasks are important aspects of maintained personhood. Julia Twigg has written richly (1997a, 1997b, 1999, 2000a) about bathing and the body work of personal care. Much that she reports was echoed in this study; Shirley's description of helping Winifred with bathing is a typical example:

Winifred's very shy that way [...] she's very private. It's taken her a long, long time [Shirley speaks quietly—and I think this is because of confidentiality] to have somebody to shower her [...] Winifred will wash herself. I'll just help, go with her to the bathroom, take her dressing gown, then she does the rest. And then she'll put the dressing gown on when she comes out, and then when we get there, we have a towel coming down here, and she just pulls that off the middle, and she's got another little towel.

I dry her back and put cream on and then, then I—'cause we have to go inside in the loungeroom, she sits in her chair to do this, 'cause she can't stand up and do it, it's just too much [...] If she washes her hair, she's exhausted and it takes us a long time to get into the loungeroom. Then, um, when I've done the back, I go and tidy bits of the bathroom, and by then she's dried the personal parts and the front and

she's got her tops on, and her undies, and then I come and, usually, she'll dry the bottoms of her legs—just depends how she is—and then I'll do that and put cream on, But I'll massage her legs for a little while when she's there, and she just, she said, it's so relaxing.

Shirley and many other workers followed personal care routines with clients that resembled their own everyday habits. Thus, Anita would, “go in and think, ‘Right, what do I have to do when I have a shower in the morning?’ Yeah—go to the toilet [...] So you know, and then, you know, you have a shower, you do the teeth, you have a shave. You know. All these things”.

For bathing, clients or residents would sit on a shower chair, or stand, often holding wall-mounted rails. Others used a bath board or chair over the bath or were moved in a hoist. Once the bather had been soaped, they or the worker used a hand-held hose to rinse. Vic and James were “a team. I pass him the washer, he gives me the hose and it's clockwork. We talk and stuff; we don't have to say it, we just know what to do”. Sometimes, the worker needed only to prompt. With Jasmine, Vic would say:

“Okay, now's shampoo time”. And she'd do that. I'd go “Lift your arms up”. I wouldn't be a scrub—I don't think I scrubbed much. Might have been her back [...] Yeah, with this one lady, and in and it was, I'd stand outside the curtain. And I'd say, “Are you doing this now?” “Yep”.

In these ways, workers supported clients to experience continuity and competence, to present an internally congruent self—that is, a self that is intact and congruent with the client's sense of themselves. Conversations about bathing were also a site where workers displayed their competence and care.

Competence and incompetence in bathing

Workers' reported performances demonstrated sensitivity to clients' potential shame and embarrassment. Tilda told me about the so-called ‘blue-bath’, in response to a photo prompt of a woman being lowered into a bath (see

Appendix F). The collapsible blue canvas ‘bath’ sits on a gurney, its sides pulled up around the (usually immobile) resident. The worker can “*access every nook and cranny that needs to be washed*”. But, “*it’s cold canvas, where they’re just sprawled out [...] you have to try and turn this slippery person, and wash everywhere*”. Tilda hated it:

They just lay flat on their back; stark naked—at the discretion of the staff who are working with them. Horrible. And not everybody has the brains to put the heaters on in the bathroom, I mean sometimes it can be stifling, but the heat has to be for the resident, not me.

Tilda was setting her own practices apart from the failures of other workers, as well as imagining herself in the client’s position. Stella, too, “*would hate to have to be naked and showered in front of people, so I make sure that I keep eye contact with them. And I’m not looking at, you know, the rest of them*”. Civil inattention (Goffman, 1963a) was frequently described, and it is one of the ways in which workers’ performed emotion work in the context of an intimate ritual. They worked to manage clients’ nervousness by, for example, leaving clients to wash their own genitals and ‘fronts’:

Like we get the shower on; we get it on at the right temperature. We say, ‘You can hop in now’. Um, get the flannel warmed up. We can put soap on it for them. Then, people often need their backs washed, and their legs washed. (Stella)

This division of bathing labour echoed what Twigg (2000a) described as a hierarchy of touch (citing Rubin 1966, and Rubin & Jurrard 1968). Shoulders and upper-arms may be touched by most people. Some people may touch knees and thighs and backs. Only ‘erotic relations’ may touch breasts, genitals and the anus.

Workers’ sensitivity was affected by gender. The overwhelming proportion of women in the workforce meant that male clients had little choice (Wilson, Stancliffe, Parmenter, & Shuttleworth, 2011, report on this factor in disability

support), but workers told me that female clients in the community commonly asked that men not assist with personal care. When Vic did, he was alert to the need to take precautions. He had *“some vagina cream I had to rub on this customer at the group house. I got another person — just because, to cover myself. Because — that’s just because we’re men — I’m a man”*. Brian was less careful. His discussion of women’s bodies was blunt. In one interview, he told me about a conversation, with an EN who was *“only a young girl”*, about personal care:

I said to her, ‘Listen darl, tell me whose job it is to trim the pubic hairs of the residents?’ ‘Pardon?’ I said, ‘This woman’s pubic hairs are so long, that, I said, ‘You remember the old ditty, ‘the hairs on her dicky-di-do hang down to her knees’? Well, close enough’.

The EN trimmed the resident’s pubic hair. Brian gave several other examples of his knowledge of women’s hygiene needs, though he admitted that *“when I first started doing it [...] someone had to tell me”*. And he spoke of several women who specifically asked that he assist with their bathing. That he had created the *“proper state of mind”* (Hochschild, 2003b, p. 7) for women to accept his support signalled his ‘client-whisperer’ skills.

As well as bathing, workers helped people to the toilet, managed incontinence and worked on the smaller tasks of teeth and hair-care. Shaving *“wasn’t that hard. You know, I’d done it for years”* (Lilla), and Stella found helping women with makeup and hair a pleasure:

I’ve been dying my hair for ever, and so I was really rapt to dye her hair for her and set it, and put it in curlers and blow wave it. And it made her, I know ‘cause of the sort of lifestyle she used to live, made her feel a million dollars.

These tasks, along with appropriate costuming, determined whether clients’ presentation of self succeeded. Again making comparisons with other workers, they spoke of *“seeing [clients] in clothes that are too big”* (Tilda) or staff who:

don't want to spend the time to make sure that he has his undies, his trousers, like his suit pants, his thin socks, his proper dress shoes, his belt, his tie, you know, his dress shirt, his tie, his vest, then his jacket. [But], you know, this man has dressed like this all his life. (Lilla)

Like Stella, Anita and Blanche enjoyed the performance aspects of assisting people to “put on their makeup, or choose something for them to wear. Or if they need, you know, they’re going out for a special occasion, you know, take their wardrobe out, ‘Oh, what pearls would you like?’” (Blanche).

Sometimes, events intervened in this presentation:

She was so embarrassed if she, you know, if she had a stain, or defecated, or [...] and you know, she’d try and wash out her own underwear [...] So, again, you, care isn’t just, “Okay, well, I’m going to give you a shower”. Care isn’t just, “I’ll wash your clothes”. There’s other issues as well. I mean, somebody should have been taking care of the fact: “Look, don’t worry about that darling. I’ll whip them in the wash, they’ll be back; no one will ever know. Clean, brilliant tomorrow”. ‘Cause that’s reassurance, and that’s care. (Brian)

In performing these tasks, workers gained pleasure—and a sense of competence—from clients’ successful presentation of self, and their own part in it. This relied, in turn, on workers being able to create the ‘proper state of mind’ in clients to accept this support.

Food and eating

Patricia wasn’t eating! She wouldn’t have Mum’s Meals.³⁷ She doesn’t like the food. Very traditional. Lamb and rissoles. Lamb and rissoles. (Joanna)

Food preparation and eating are sites where continuity of personhood was achieved or damaged. Joanna’s reference to lamb and rissoles hints at the

³⁷ Mum’s Meals was a widely used meal home delivery service.

importance food choices have for identity (see Philpin, Merrell, Warring, Hobby, & Gregory, 2014).

Meal preparation was frequently a shared activity. At Harvest, where most meals were supplied by external commercial kitchens, Tash cooked on Saturday nights and staff brought in fruit or “*treats*” to share with residents. Tilda would sometimes make snacks for residents at Shore View, and Brian talked about encouraging residents with dementia to help themselves in the kitchen where he worked. In the community, many workers and clients prepared and cooked food together, or workers readied parts of a meal for the client to reheat later.

I watched several food preparation sessions and meal times. Shirley prepared three meals for Winifred. Though her appetite was small, Winifred enjoyed cooking. Mindful of Winifred’s interest, Shirley arrived when I was there with a bag of home-grown vegetables and a jar of pickle. Shirley took “*some vegetables over to Winifred asking about the size and what to do with them. She shows Winifred some pink eyes [potatoes]. Winifred then plans what to do with the potatoes. Winifred says of the potatoes: “Oh, aren’t they lovely”* (Fieldnotes, observation). Such attention to the particular tastes of clients was evident in many interactions. Joanna brought a book of recipes for cooking Olivia’s favourite vegetable, and Anita and Sally pored over cookbooks together, talking about TV chefs, planning and budgeting for the week’s menu and working together in the kitchen.

Sometimes, though, food undermined clients’ and workers’ presentation of self. Olivia reported that she and Blanche disagreed about how long vegetables should be cooked, and Anita told me about a client who would rather entirely reject the worker than complain about the food she was generously (though with cultural insensitivity) bringing. Workers in facilities spoke of the lack of respect for the diners conveyed when food decisions were made by senior staff with—as Tash saw it—little thought for the consequences. Several people

reported lifelong vegetarians being served meat, and meals being badly prepared and served with indifference.

Such discordant interactions meant that workers could not demonstrate the competence Joanna proudly reported: *“What I do in that hour is amazing. Because I plate up at least four meals for her, with little instructions written on there, how to warm it up in the microwave”*.

Social interactions: Eating, control and stigma

Correctly performing the social rituals surrounding eating is also a significant part of the presentation of self. Effective impression management includes adherence to the etiquette of eating, and the control over impulses and bodily functions that entails (Elias, 1978; Nijhof, 1995). Eating is *“this very social event, and you don’t want to just be going [mimes robotic spooning food in] [...] you’d sit and have a conversation with them, like you do with other people when you sit down and have a meal”* (Tash). But difficulties with unwieldy cutlery, chewing and swallowing make this a site where clients can be disabled by social norms and expectations—and by workers.

Raphael had restricted his diet to things that did not drip and could be cut into small chunks, matching Nijhof’s (1995) findings that people with Parkinson’s disease altered their eating habits to minimise the risk of shame. Lilla, too, worked to reduce potential shame, describing her *“taking my time”* approach: *“giving [the resident] sips of fluid in between times so that she could swallow”*. This contrasted with the *“shovelling food”* approach of another member of staff. Tash was *“indignant”* about the residents’ clothing protection being called *“a feeder”*: *“There’s one lady that wears an apron and there’s another one that wears an adult bib [said in a sarcastic tone]—and it looks like a bib. I’m sorry but that’s what it is”*. Photo prompts sparked several remarks about such babying (see Figure 5.1, and Appendix F).



Figure 5.1. Food photo prompt examples

Along with child-like protection of clothing and other signals of institutionalisation, food and eating could be medicalised. In facilities, weight

loss is one proxy for poor quality care.³⁸ Thus, residents with eating difficulties are given particular attention. Brian, Miriam and Lilla conversed about a man with Parkinsonian dementia:

Brian: I watched him two nights in a row and said "He needs to be a feed". So, what do they do? They had him assessed by a speech pathologist.

Miriam: Did they really?

Brian: Yep. And then he became a 'soft'.

Susan: Ah—so instead of having proper food, he's got pureed, or ...?

Brian: Yep. And he became a soft.

Lilla: Only because he couldn't get it to his mouth. Nothing to do with the fact that he couldn't chew.

Putting aside the labelling of a resident as "*a soft*" and "*a feed*",³⁹ the remainder of this story illustrates another way in which food can be a site of loss for residents.

Meals were an opportunity to make people "*feel at least like they're getting valued in the sort of food they're being given*" (Lilla), a remark that seconds Sidenval, Fjellström and Ek's (1996a) findings. They wrote that residents' "sense of dignity, security and control was connected to their meal and food habits" (1996, p. 220). Force-feeding, or 'shoving' food at residents is a strong signal of residents' lack of power. Workers in Åkerlund and Norberg's (1985) study were similarly disturbed that the line between persuasion and force-feeding was far from clear. There, too, mealtimes were "a source of conflict and anxiety" (Åkerlund & Norberg, 1985, p. 212). The instances workers reported to me of

³⁸ Difficulty with eating and swallowing, and thus weight loss, are also part of a normal decline towards the end of life—particularly for people with dementia (e.g., see Palecek et al., 2010).

³⁹ There is some evidence (Mintz, 1992) that this sort of 'tough speech' functions both as shorthand, simplifying communication between staff, and as a means to distance staff from the risks of encounters with frailty (and see Bedell, Graboys, Bedell, & Lown, 2004).

residents being othered or infantilised, made to feel incompetent and helpless (Sidenval et al., 1996, p. 220), and having reduced or no choice, were potential sources of shame and of failed presentation of self.

Risky work

In working for the continuity of historical or everyday lives—the presentation of clients’ self—participants were sometimes challenged by ‘difficult’ clients, physical and financial dangers, and emotional risks. The ‘client-whisperers’ reported their competence at working with resistive clients and residents.

Workers also faced the challenges of working with excretions and leaks, with people who were sometimes violent, and of the financial costs of their work.

Aged care and disability support workers’ public image (see Chapter 4), low status and poor pay could undermine (or drive) their impression management endeavours. Poor pay was exacerbated by some organisations’ practices.

Minimising costs enables organisations to provide more services, but many used rostering and work-related travel in ways that disadvantaged community workers.

Driving created physical and financial burdens. Usually, workers drive their own cars for work, being paid a per kilometre allowance. This applies to most journeys between clients.⁴⁰ Joanna felt the roster was organised “*with absolutely no consideration for people’s lives*”; saying that the “*amount of travelling [...] really got me down*”. Shirley’s experience of regularly driving more than one hundred kilometres a day was not unusual. Workers also reported that some organisations imposed a daily limit on the number of kilometres for which they could claim:

⁴⁰ If the time gap between clients exceeds an hour, the wage for that time is significantly reduced.

Brian: *They'll only pay ten kilometres. That's it. After ten kilometres ...*
 Susan: *So if you take him out somewhere, you're only allowed to go ten kilometres altogether?*
 Miriam: *Allowed ten kilometres.*
 Brian: *Five kilometres out, five kilometres back.*
 Miriam: *But they're right down whoop-whoop. Oh for god's sake.*

Unpaid mileage can be claimed as a work-related expense on income tax returns, but, as Joanna remarked, *"that's twelve months down the line!"*.

Dealing with disgust

Workers deal with bodily leaks and excretions that could readily compromise clients' presentation of self. Residents and clients may be incontinent, have discharging wounds, PEG tubes or catheters or uridomes, or produce vomit, phlegm, or copious saliva. Sights and smells could disgust workers:

Trying to get in and clean their teeth is just like [Tash mimed turning her head away while looking out of the corner of her eye at the tooth brush and target] [...] you know, morning breath sort of knocks you over [...] [more of that screwed up face at bad smell] 'It's six o'clock in the morning. Don't breathe on me!' [both laugh]. (Tash)

Several workers reported finding that others had left such important presentation tasks undone. Incontinence pads were left unchanged, showers refused or not offered, and teeth ignored. Anita told a case manager that she, *"went to clean [a client's] teeth, and I nearly vomited; it was really gross. [...] Um, they were black, they were slimy, they were horrible. And they had a hole in the denture"*. She was *"really grossed out by it [...] It makes me feel sick, and so imagine what it's doing for him"*.

Such empathy was the most common response reported by workers. For these participants, dealing with excrement, vomit and urinary incontinence were evidence of a shared reality. As Miriam said, *"Like it's not a big deal. Like it's just nothing to you [...] You've really got to feel like it's nothing to you, otherwise they'll*

react to you. You don't go, 'Oh god!'". Anita repeated the underlying theme—*"we're all human; it all happens to us"*.

Equanimity was not the universal response. Tilda commented that *"Every now and then you get residents at work who've got faeces from [as in, all over the place] mmm. So there—a bit more of the unpleasant side"*. She went on: *"I hate vomit worse, actually. And none of it's pleasant "*. Tilda told me—twice—about an event that was 'a big deal'. She found a client on the toilet, and the floor:

almost covered with faecal matter. And I opened the door and she was in tears, she was so embarrassed. I didn't have gloves or anything. [...] Um, I rang [the case manager] and I said what was happening and she said "Do you want me to come and help". I said, "Yes, please". And because she wasn't that far away, she was there within ten minutes. So we both—all I had done by that stage, I had got some towels and put over it, and, and um, she, yeah, we just stayed until it was done... [But] in assisting this lady in that situation, if I hadn't have been turning up then, you wonder what would have happened. Because she, it was literally just pooled around her. What could she have done to maintain her dignity, clean up?

Tilda chose to get help so that the woman could *"maintain her dignity"*. She told me that the woman was deeply embarrassed by the event, and had repeated *"'I'm sorry. I'm sorry [Tilda's tone is of mimicking the woman's distressed tone—high pitched and a bit whiney]'"*. Tilda expressed a particular dislike for *"cleaning poohey bottoms [and] I don't like cleaning pooh off testicles [T was making a face and holding her arms outstretched]. Gross. I'd rather hose them down!"*. She had a solution for masturbation and semen smells: *"I think they should be castrated! [laughs] They don't need them"*, and reported examples of her humiliating treatment of male residents who masturbated. Perhaps her own embarrassment made it impossible for her to react with equanimity. Residents' violations of social norms were failures to present competent selves. They prevented Tilda (and others) from demonstrating their own competence.

Protection of and protection from: Gloves and masks

To deal with the leaks and excretions, workers were expected to comply with health and safety guidelines. Wearing gloves is prescribed for contact with “non-intact skin”, “blood, body substances, secretions and excretions”, as well as for handling soiled laundry and other objects, for handling and preparing food and emptying vacuum cleaners (National Health and Medical Research Council, 2010). Workers knew the guidelines, but with one exception, no one I observed seemed to always follow them.

Shirley said, “We’re supposed to wear gloves most of the time. So, normally I do—most of the time [smiling]”. When I observed her working with Winifred, she was meticulous; she wore gloves as well as frequently using hand sanitizer lotion. This could be laborious:

... [another] lady that we have to wash, that’s in the wheelchair, I do wear gloves, because I’ve got to wash her bottom and all that as well. It’s for her sake—when I’m washing her I’ll, I have a pair, ‘cause I’ll do the bottom and that last. I have one pair to do this bit, and then I have another pair of gloves to do the other bit, and yeah—I have used lots of gloves there.

Shirley was the only person who wore gloves while preparing food. Blanche wore gloves while cleaning, and Stella put gloves on to do the mopping, then wrung out the floor cloth and took her gloves off, but neither wore them when handling food. Nor did Anita or Edwina, although both prepared food and helped with some personal care (both washed their hands frequently). Justin did not wear gloves while making lunch, but washed his hands between preparing and cooking.



Figure 5.2. Safety gear photo prompt examples

I asked workers who were not in the dyads about gloves. Also, some photo prompts showed protective clothing (Figure 5.2, and Appendix F), or depicted situations in which gloves would be a workplace health and safety (WHS) requirement. No-one commented on the fact that workers were not wearing

gloves in any of the photographs of bathing, food preparation or eating. Vic's response to the glove photos illustrated that he was careful about his own and the client's safety, and wore gloves, *"especially if we're giving [John], with his meal, we glove up—with his PEG [...] 'cause what we're doing is twisting his [tube] with our hands"*. Working with John required precautions, since *"he's hepatitis C positive"*. In residential facilities, workers are, as Vic put it, *"always dealing with penises, genitals; we put the gloves on"*. *"I think it makes sense. Like 'cause, you don't want that on your fingernails and stuff, I guess"*. But, *"Gloves are annoying—seriously [both laugh]. [...] I'm pretty lax with gloves; I only use them if I have to"* (Vic). For wound care, gloves protected *"them from me, rather than me from them, because I reckon I'd probably carry more germs than what they do"* (Tash).

Vic gave another reason for not wearing gloves. Hurting James or John was anathema to him:

I mean like it's more about [the clients' needs]. Like with James, I started to use gloves [...] Then you'd rip his leg hairs, or whatever. You can't do that. Yeah. It's horrible latex stuff, yeah, [...] I just wash my hands real properly, really, really well. Lots of HeX around the place [...] James is real sensitive [...] —if he has a leg bag to empty, that uridome, the leg bag goes down to the uridome, so you roll up [his] pants and empty it. If you touch his leg with your glove, [...] He's got quite hairy legs like mine actually, he, he'll jump [laughs very briefly]. Not jump, but he'll "Ah, oh". "Oh sorry". So I never use gloves for that.

Sometimes, Vic wanted to *"wear a mask! Especially around John when he's coughing, but [...] I think it's disrespectful to him"*. Instead, he chose to *"just sort of turn around or, if he does cough, put our glove up—if we've got a glove"*. In these choices, Vic was maintaining clients' presentation of self rather than signalling their status as leaky or contaminated.

Tilda, on the other hand, who had not had gloves with her when the client had the faecal accident she told me about, also said that *"You won't get me doing anything without gloves—even putting cream on people's feet"*. She gave the

example of a resident who had fallen and was lying in “a pool of blood”. “The RN on duty said, ‘Make sure you have gloves on’. I’d like to think it was because of all the blood, and, you know, just for safety, because the next thing was, ‘You never know where she’s been!’”. In the event described above, gloves seemed to fulfil a function of protecting Tilda from the resident; they also signalled judgement and disgust. She made another mention of gloves, again signalling this latter function. Complaining that there was a “real semen smell about a couple of [residents]” — “you know when they’ve had their hands down there, ‘cause they quickly move them out when you go into the room” — she said, “it’s gloves on, wipes, ‘Let me just give your hands a wash first’ [school ma’am tone]”.

Workers’ responses to gloves are congruent with Twigg’s (2000a) description of gloves as a physical and symbolic barrier that could position the worker as a professional working ‘on’ the client. Gloves underline “the limited character of this kind of touching”, protecting the worker from contact that was “too direct and too intimate” (Twigg, 2000a, p. 151). Tilda was wary of this intimacy, reinforcing their otherness. Most workers, though, focused instead on clients’ and residents’ responses to gloves and other protective clothing, appearing to prefer experiencing their shared humanity.

Physical and emotional risks

By the time I get home on Friday night, I think ‘Ha—how am I going to get up tomorrow?’. But you do. (Shirley)

Workers face contamination and infection as well as the risk of injury from bending and lifting. They could also be exploited and abused, and faced dealing with their own and clients’ grief and other emotions.

Several people in the study had back and other injuries. The second time I met Tash, her wide smile appeared a little less frequently. Her ankle was thickly bandaged: it had been sprained and possibly broken at work. She told me she

had also damaged her lower back, assisting another worker to lift a resident, and in her first support work job she had worked with people with “*violent behaviours*”. As well as bearing the brunt of “*yelling and screaming*”, she said, “*it would be nothing to get a punch in the mouth or a kick to the head [again, smiling], or [...] Yeah, pushed over, or whatever*”. Tash’s experiences were not out of the ordinary. Brian had had “*both me lips split open*”, “*me knee cap kicked up around the top of me leg*”, “*me knee wrenched by a bloke falling on me. And, yeah. I’ve had a bloke spit in my face—I didn’t like that at all*”. Sometimes injuries were described as being caused by residents or clients; more often workers took responsibility themselves.⁴¹

Sore or injured backs were almost routine for workers. Shirley’s back was not “*the best*”, but she “*just shut[s] up and get[s] on with it!*”, and Anita had lifted “*a client when I shouldn’t have*”:

Ah, she was the tiniest little thing, too [...] she had a bath [with] one of these, um, seats that go down, battery operated. And I’d been saying for a few weeks, “That battery’s playing up. I really need to get a new battery for there”. So I got her down this time and of course there was no battery. Couldn’t get her out. Sunday, too. And, um, and she was an epileptic as well, so I couldn’t leave her and I hadn’t taken my phone in; it was out in the car. And I was a bit nervous about [leaving the room]. So, um, her, because she was so tiny, I lifted her out.

Workers are expected to seek assistance to lift people—from a co-worker or by calling the ambulance. Tilda and Joanna reported having done so. But when I talked with Vic about a client in the study who reported having fallen and been picked up by a support worker, his immediate response was “*Of course, yeah. I*

⁴¹ Presaging the discussion of worker self-care later in this thesis, it is interesting that there is evidence that depressed people tend to make internal attributions about their failures and external attributions about their successes (see Forgas, 1998; Langridge & Butt, 2004).

mean any good person would do that. If you could". Vic was presenting a compassionate self, created in his work for the presentation of a client's self.

Three women⁴² in the study talked about incidents which highlight the risks of working alone. These experiences *"really made [them] think how vulnerable we really were, going in to people's places"*. One of the women was *"just floored"* by a community client's accusation of theft that took some months to resolve.

During this time, her employers appeared oblivious to her anxiety. She was left shaken, angry and concerned about her practice and about how the organisation had responded.

Another woman had a client who had *"started masturbating in front of us. And he cornered one of the girls in his house"*. Her job required going *"in there at night"*:

He'd go to bed quite early—the house would be dark when I walked in, and I would be really scared that he was behind [...] I'd have my phone on me again ready to go, and I was just on edge the whole time. And you turn all the lights on as you go through the house and eventually you'd go into the bedroom and he's put himself to bed. Which was cool—but then you still had to get him some supper and all that and you're just watching your back the whole time. 'Cause he was quite a big man as well.

Going into people's houses can put workers into unsafe family dynamics. One woman had provided services to a person experiencing domestic abuse. She reported all such incidents back to the case manager who *"tried to help [the client] to move out"*. In the meantime, the abuser was often present when the worker arrived, *"and of course one day I, um,—he, he got narky towards me"*. Encounters like these left the worker's stomach *"in a knot, every time you walked in there"*.

⁴² The workers in this section are not named here, since the events they report may be readily identified.

Many workers had been injured (accidentally, intentionally or as a result of a client's cognitive or behavioural impairment), and worked with clients who had been or are experiencing abuse. They faced people who were known to be violent or sexually aggressive, and experienced being physically or verbally abused and situations that were disturbing or traumatic. These events, which were not isolated, are evidence of workers' vulnerability and contrast with the literature and media (Chapter 4), where themes of vulnerability and risk focus on clients and residents. Despite the risks and their fears, most workers remained concerned about their clients' needs, saying: *"someone has to help them out, and the problems can be overcome. Mmm. You can't just run away when a client — things — get difficult"* (Stella).

Risks to emotions

Workers were involved in the emotional lives of clients, and in negotiating their own emotions in their work. Confronting and dealing with 'failures' of the body (Isaksen, 2002; Twigg, 2000b) is emotionally risky. Isaksen (2002) has described care work as constantly reminding workers of their own fragility; workers see illness, leaky and unpredictable bodies, neglect and decline. Failure to manage fear, embarrassment, grief, or shame may result in their being unable to perform the required tasks, or in their disabling or stigmatising the client. When I asked Jai whether the disabling (or cruel) acts he had witnessed workers perform reflected lack of training or something else, his response was that *"it can also be stress. It can be tiredness. Tiredness plays a big part in it; like you know, it's taxing physically. Um, and that, the frustration can be too much"*. Jai knew the work could *"get exhausting, particularly if, um, if people are dying, continually"*.

Almost all workers had experienced the deaths of clients.⁴³ Tash and Anita, who had been required to provide palliative care to people they worked with, felt unprepared, as Anita revealed when she recounted the following story. She had been called in to spend a night with a woman who was close to death:

Oh—she was just a mess. Plus she had dementia. [...] Um, so I sat up all night with her. And she was just like a frightened little rabbit; it was horrible. And she just kept saying, “Please god, just take me. Please god, just take me”. She’d sit up and say this [...]. For the first couple of hours, she was not responsive to me at all, and then by the, come morning time, I was in bed with her. ‘Cause I thought, “She just needs to be, to feel secure”. And I, so, from about three o’clock I suppose, I just got in bed and cuddled her. And then she died the next day, and—I—she looked up at me and she said, “Thank you”, when I was in bed with her.

At home, Anita talked to her partner about it, telling him that she “*didn’t know what to say to her. You know, and I didn’t know what—...but it was the fear of not knowing. I think, you have this fear about death, and well, what should I be doing?*”. In the absence of training or instructions, Anita had to work it out for herself:

... I think whatever you feel you need to do. And, like, I was thinking, “What should I be saying to her?” Oh, we sang, I sang “Amazing Grace”—the only thing I could think of; I didn’t think she’d like Pink [both laugh].

Anita had to manage, and did so.

Workers managed their own emotions in order to sustain “the outward countenance that produces the proper state of mind in others” (Hochschild, 2003b, p. 7). They also worked to ‘produce the proper state of mind’ in clients that would allow work to be done. Hochschild identified such emotion work as a skill that adds value to a work role (2003b, 2011, 2012). Yet emotion work or emotion management in aged care and disability support work has only

⁴³ Three of the study’s participants died during the study—Sally, Norah, and Cornelia. The impacts of these and the other deaths and illnesses comprised a sub-theme in the data; this material will be reported elsewhere.

recently been given specific research attention (Gattuso & Bevan, 2000; Kessler, Heron, & Dopson, 2015; D. King, 2012). Participants' emotion work was, as Joanna said, *"never mentioned"*, but it was expected that workers would manage the emotionally risky encounters of aged care and disability support. The expectation—in this study—came partly from provider organisations and partly from care and support roles being naturalised to women, the people who make up most of the workforce. But the naturalisation was also lodged firmly in the workers themselves.⁴⁴ Clients who were sad, very unwell, or depressed could leave workers feeling *"a bit flat yourself because it's just—there's nothing you can do [...] I think that's an expectation you put, we put on ourselves"* (Anita).

Workers were expected—and expected themselves—to 'manage'. They talked about ways in which they produced the 'proper state of mind' in themselves:

Like I was saying about that nasty lady, in Misty Valley—every single carer used to walk [up to] her house, and just wish they, just think, 'Oh my god. I wonder what I'm going to get today'. So you do have to adjust. [I sometimes] can wake up in the morning and go, 'Oh no—it's Monday. I've got that client'. [...] You go, 'Okay, after I get over that person, then the rest of the day'll go well'. But you've still got to go in there smiling and act like you're, ... Kind of—it's hard work!
(Blanche)

Workers adjusted their performances. *"Because they're people,"* said Joanna, *"you have to be different with every single different person, 'cause they all have different needs"*. Putting *"a lot of work into connecting"* with particular clients *"took a long, long, time"*, but *"it was definitely worth doing"* (Ruby), enabling what Jai called the necessary, *"genuine engagement with the individual"*. And, since conditions change, workers needed to *"change within that relationship as well"* (Jai), reflecting on their practice and beliefs. Anita gave an example: *"When I first*

⁴⁴ Clients may appear to have this expectation; I assume that their own awareness of the potential for stigmatisation is at least partly causing a sort of denial of the worker's risk.

started, one client said to me, 'I just want to die. I just want to die'. And I was horrified. I said, 'Please don't say that.' I said, 'We're here to make it better for you!'". Until this moment, Anita said, she had adopted the cheerful breeziness (not unlike that of one of Hochschild's flight attendants, 1983) I had seen in Stella's performances with Raphael. After this encounter, Anita thought about the woman's situation and realised:

We can't make life more enjoyable—we can just make it more comfortable. And now when they say to me "I just want to die", I say, "It's really hard, isn't it? Can I do anything to make you feel better?" I don't say, "No, you don't"— 'cause that's stupid.

Workers wanted to do a good job in sometimes difficult circumstances. This required a great deal of management of their own emotions to adapt to the encounters they had, and to maintain their own and clients' 'face' (Goffman, 1967). But most played down this skill, and employers seemed not to recognise the effort involved.

Self-care?

Workers' presentation of self as competent and caring can, as Jai noted, be compromised by exhaustion and frustration—and by grief. Long shifts of what is effectively manual labour, combined with emotionally draining encounters exact a toll on workers. Some workers had long periods away from work and several spoke of the cost to their emotional health, including their experiences of depression (and see Ahlström & Wadensten, 2012; Geiger-Brown et al., 2007; Gray-Stanley et al., 2010; Macpherson, Eastley, Richards, & Mian, 1994; Margallo-Lana et al., 2001). One worker—Tilda—was careful that our meetings would be away from public eyes because, as she readily reported, she was *"teary"*, meaning emotionally fragile. Her history was littered with emotional insults and personal losses (that were still very fresh to her) including the recent deaths of several family members and friends, her own struggles with illness

and addiction, and the thwarting of a long-standing ambition. I asked her whether she had used her employers' counselling service. She had not. Like all the others I asked, she knew there were counselling or other supports available but either did not trust them, or had internalised grief as a normal part of the work and viewed emotion management as evidence of competence. I wondered if workers feared that grief might reveal their officially frowned-upon closeness to clients.

All workers spoke to me about clients' and residents' deaths. Illness and death were constants in their lives. Some experiences, though sad, were opportunities to work for a client's final performance; they spoke of laying out as a way to honour the person. Other experiences were unrelievedly sad, and were made worse by external factors. The death of Sally (Anita's dyad partner) was an example of the latter.

Sally's health had been declining and she had a series of falls that exacerbated her existing conditions. When Sally's decline was most precipitous, circumstances beyond her control took Anita away from the dyad relationship. Though Anita telephoned Sally and sometimes visited, she was not doing support work, and Sally had been unreceptive to visits and phone calls. When I phoned her during this period, Sally was worried and distracted, though her more familiar genial straightforwardness remained. That is not surprising, but Anita had felt excluded. She talked at length (a month after Sally's death) about her feelings. Disappointment and guilt at being unable to 'be there' for Sally were prominent:

But [Anita really sounds dry-throated here], I will always regret that I didn't get to see her in those, those last few weeks. I should have known. I mean—I'm working through it, but I should have. I should have known [...] I'm thinking, "Why, why did you allow that to happen?". So I'm still working through the process of how,

why I allowed that to happen. Because, the day Sally died, I didn't see her before she died.

Anita took sick leave, and when she finally felt ready to return to work, found it difficult to manage her sadness and again took time off. Several times during our interview she was close to tears,⁴⁵ and she also made some wry asides to her (dead) partner during the conversation: “[looks heaven-ward] *It's all about Sally — it's all about you, Sally!*”.

As well as having to deal with the fact of Sally's death and her own perceived failure to 'be there' for Sally, Anita was angry with Hillcrest. They “*didn't notify me that [Sally had] died*”. This was despite a recent staff meeting where “*the support workers had asked, could they not get a text message,⁴⁶ could they get a phone call to say one of their clients had passed away. And everyone was in agreement with that*”. Hillcrest had not handled it well. Anita talked about several ways in which her attempts to help Sally (reassuring her about her pets, for example, when she went into hospital) were discouraged or actively foiled by Hillcrest. The organisation's lack of care for workers was again evident.

What shapes practice: Agency, rules, boundaries and provider organisations

The degree to which workers were able to successfully present themselves as competent was affected by their own capacities, expectations and attitudes, by clients' responses, and by the rules and boundaries established by provider organisations. Agency, here, I take to mean the capacity individuals have to influence circumstances and events (Berger, 1963, p. 199).

⁴⁵ Anita had suggested the interview, after she emailed to let me know Sally had died. I offered to stop the interview when Anita was upset, but she declined the offer.

⁴⁶ Receiving news of clients' deaths via text was not uncommon.

Agency

Some workers seemed to have more resources, be less battered by the emotional demands of their work and lives, and be more resistant to unreasonable demands. This made me suspect a link between agency, self-care and the capacity to work for the presentation of self desired by another. Joanna, for example, refused to put up with what she saw as unfair work conditions and placed limits on her exposure to dangerous or difficult clients. She resisted poor practices like the blurring (by organisations) of medication rules and was perturbed by case managers' failures to respond to reported clients' needs. Before the end of the study, she resigned in response to repeated and accumulated organisation failures. Invited to an exit interview, she imagined her concerns would be taken seriously, *"but [they weren't] interested in hearing it"*. Joanna's response was *"Stuff you! You know, my life is short enough as it is; I don't have to deal with that"*.

Leonie had rejected what she saw as institutionalising and unethical behaviour and had become an independent operator, running her own support-related business, some years before, and Ruby had 'escaped' residential support work for a day centre role. Vic, resigned from Harvest because he felt his abilities and knowledge were not valued by more senior staff and administrators. Jai managed his dis-ease with the hierarchy by doing brokered⁴⁷ and night-shift work, and then moved to a higher status health sector role, as did Brian.

These six workers—who all reported highly enabling interactions with clients and residents⁴⁸—demonstrated agency in their resistance to what they saw as demeaning or unfair employer practices. They were attentive to their own, other workers' and clients' well-being. They believed in their value as workers

⁴⁷ Casual, on-call work for care and support organisations.

⁴⁸ These reports were corroborated—sometimes by clients, sometimes by my observations (before the event) and sometimes by co-workers who were unaware of these workers' participation in the project.

in their role, but were not restricted to it. They resigned, confident that they would find work. This too implies agency, as does Brian, Ruby and Jai's preparedness to work for higher qualifications (a further example of Hochschild's 'status shield', 2012).

Other workers, though, demonstrated very variable levels of self-care and a range of responses to system failures. Where clients' needs seemed to be unmet, they tried to make up the shortfall. Some were resentful about their clients. Compounding somewhat poor life chances, the working lives of the people (Blanche, Tilda and Tash) in this last group had been affected by partners whose careers had taken precedence. For Blanche, for instance, the time she might spend with her husband or family seemed of less value to her than did the time she spent with clients. Or was it that her need for rest or time off was not met at home either?⁴⁹ Were the satisfactions of support work—where she was (usually) appreciated—greater than those of home? She ruminated that sometimes *“we care about people and we do these things selfishly, 'cause it makes us feel good about ourselves”*. *The work enabled her to present—or perhaps create—a self that made her ‘feel good’*.

Control and regulation mechanisms

Workers' desire to work for the continuity of clients' presentation of self was constrained by external forces. They were, for example, expected to enforce social norms, and these could shape choices around food and eating, bathing, clothing, household cleanliness and ways of living, as well as clients' and residents' sexuality, smoking, drinking, and whether they took their prescribed medications. Anita saw such work as a form of policing. She talked about the pressure one client was under over their right to choose whether or not to take medication, which:

⁴⁹ Information Blanche gave me about her home life indicated that it offered little sanctuary.

gives her hallucinations. Mmm—horrible. And so, she chooses not to take the medication, sometimes... and there was one particular worker that kept going back to the case manager and saying, "She's not taking this particular medication". And the case manager was getting on her case, saying. "You've got to take them. If you don't take them, you know that you are going to get the shakes back, you know, all this is going to happen".

Norms could also be imposed by family members. Miriam, Stella, Vic, Lilla, Tash, Brian, Blanche and Joanna told me about family members insisting that their own beliefs and norms (about smoking or sexuality, for example) be followed, regardless of whether they were shared by the client or resident (and see, Bazzo et al., 2007; Benbow & Beeston, 2012; Hamilton, 2009). Workers sometimes complied to avoid “*aggro*” (Joanna) between themselves and clients’ or residents’ family members.

Time was by far the most talked about external factor shaping service interactions and clients’ lives. Time is “the key control mechanism, [...] used as a proxy for service delivery to users” (Rubery, Grimshaw, Hebson, & Ugarte, 2015, p. 4). Time signals the “volume and quality of service” (ibid., p. 5). Workers had to match clients’ lives to timetables driven by funding and rostering: “*You know, and to be told when they have to have a shower, and told when they have to have tea. And I mean that’s so routine for them now*” (Tash). The twelve people who had worked in residential facilities found the demands at the start of the day there particularly problematic. Edwina reported that, “*you know, this, this, this has to be done [makes chopping gesture] in a certain time. There wasn’t as much time to get personally acquainted with people and really know the essence of people—because it was like that production line*”. While the reported time allowed for waking and preparing each resident for the day varied, the consensus was that it was very short, and Edwina’s chopping gesture was repeated by Tilda, Jai, Lilla, Miriam and Vic. Regulation, applied in facilities where Jai had worked, meant that “*to be honest, it feels like, [...] [residents] are a commodity*”. All

the workers resented these constraints on their work, on clients and residents, and on the possibility of knowing “*the essence of people*”. Time pressures had been an important factor in several workers’ decisions to move from residential aged care and disability facilities to community work.

But constraints were also present in group houses and in the community. For Shirley, rosters that allowed six minutes for showering a person were counter-productive, since:

you just can’t push them. I can’t. I mean, I couldn’t say to Winifred, “Come on—hop in! Come on,” you know, “move it!” You just, you just can’t move them. They just get so overwhelmed and that’s when things start to fall apart.

The risk of agitation and accidents caused by rushing people compounded workers’ dislike of imposing someone else’s timing onto an independent person. Rushing had sparked several ‘heated discussions’ between workers and rostering and administrative staff. Anita had complained to case managers, saying “*I’m sorry, but you’ve got to understand, you can’t walk into these people’s place and say, ‘Okay—clothes off, into the shower’. Can you imagine that? ‘Don’t talk! Don’t talk to me. Just got to dry you’ [held up hand]*”.

Some restrictions left workers unable to create or sustain clients’ presentation of self, and their own performance was thus compromised. To compensate, many workers broke the rules imposed by workplace health and safety legislation (WHS), as well as employers. The former was intended to protect individuals from injury or illness; the latter focused on shifts and travel, what is and is not part of the work, relationships, and confidentiality (Table 5.1). Every worker in the study transgressed boundaries in one or more of these areas—sometimes significantly.

Table 5.1. Provider organisation boundary rules/policies

Boundary area	Rationale	Internally or externally mandated
Tasks regarded as potentially dangerous: changing light bulbs, climbing ladders, lifting people, etc.	Minimising risks to workers and to clients (and, legally, to organisations)	Employer duty (legislated) to maintain a safe working environment—WHS
Personal matters: <ul style="list-style-type: none"> • Disclosure of personal information (either person) • Forming friendships 	Confidentiality Risk to both parties of revealing information which might lead to conflicts of interest, or to burdening (or putting pressure on) the client, for example Conflicts of interest	Internal organisation policy is usually to discourage personal relationships
Working outside rostered hours	Support to be carried out in allotted time. Injuries sustained in un-rostered time presents a compensation grey-area	Internal organisation policy strongly discourages this
Advocating	Workers may advocate for things which will directly or indirectly benefit them (e.g., result in more hours of support, or social or other support which they enjoy)	Internal organisation policy Independent advocates available

Workplace health and safety (WHS)

I observed, and workers, clients and facility residents told me about, numerous WHS breaches. Participants treated such breaches as an open secret. Bill laughed when he told me “*there are so many caveats on what Brian can and cannot do, that it turns out that he can’t do the things that Delia can’t do either*”.⁵⁰ If Brian did change a light bulb, Bill joked, it was “*done by some sort of osmosis that he doesn’t have anything to do with*”. Joanna spoke of a worker who “*brings her own vacuum cleaner. She shouldn’t do that but—you know—this is what we do*”. Even

⁵⁰ Brian told me about Delia’s habit of doing the housework for which he was paid. He understood her reports of cleaning, of setting the fire, of managing money as central to her identity, contributions to the project of family and marriage (roles she spoke to me about with pride).

Stella, the community worker who most conformed to organisation rules, said, *“sometimes it’s just easier. If we know that we’re doing it safely. I mean, you know, you don’t get on a wheelie chair and do it, or anything”*. Changing light bulbs and getting up ladders were the most frequently reported forms of rule-breaking. One client photographed, with agreement, her dyad partner fetching a board game from the top shelf in a cupboard, describing this to me as, *“so that’s her getting up a ladder, which she’s not supposed to do”*. There were numerous other breaches for which workers provided rationales. The requirements for wearing protective gloves were far from religiously followed, and guidelines about lifting were also clearly being ignored.

Personal matters

Part of the work of producing the ‘proper state of mind’ took the form of talking about personal aspects of their lives:

Well, strictly speaking, we are not allowed to get emotionally involved with our clients at all. We’re not supposed to talk about our personal lives; we’re not supposed to. But how can you not? [...] They’re not just a client — they are people.
(Joanna)

Most workers saw an inherent conflict between requirements to deliver person-centred care and keeping a professional distance. Asked about whether he complied, Jai responded:

Absolutely not. I disagree with that — 100 per cent. It inhibits, um, any rapport that you can create with your, with your, um, resident. And it takes away from the personal experience of, of everything. And it turns that person into a commodity. And, which is not what they are. So that’s why I don’t subscribe to that!

Such distance would mean that *“you don’t receive anything back, so your work is very unsatisfying”* (Jai).

Many workers spoke of the social isolation of clients. Perhaps for this reason, several had given their phone numbers to clients. All Anita’s clients had her

number, *“because a lot of them don’t have transport, so therefore, if they know I’m going at a particular time, they may need milk or something, whatever. So to me that’s vital, that they have that”*. Another consequence of perceived isolation can be that workers sometimes suggest social activities in place of instrumental tasks, such as Blanche’s proposals to *“garden with them, or, you know — ‘How about we go out for a coffee instead of doing the housework?’ — that suits me [laughing]!”*. The risk that workers shape support to meet their own wishes is one reason that organisations give for proscribing close relationships between workers and clients. Tash also pointed out an associated risk, so-called ‘cherry-picking’: *“what about all the guys that see you taking somebody home but never get asked if they want to go for a drive?”*.

Given their rejection of the don’t-get-personal rule, it was not surprising that workers were also not compliant with the stipulation that they avoid friendships with clients. The magnitude of this relationship dimension called for the categorising of a separate theme in the findings (Chapter 7): “Co-constructing meaning”.

Working outside rostered hours

In keeping with their concerns about having too little time to meet clients’ needs, several workers were doing unpaid extra work. All organisations state that over-work or non-prescribed work is against their policies and workers and clients said they were aware that breaches could result in disciplinary action. Workers in facilities may do ‘extra’, but it was usually restricted to missing breaks while spending time with a resident, for example, or occasionally bringing in something from home to share. But I both observed and was told about work in the community done outside rostered hours (unpaid), or that breached the professional boundary.

I observed Sally and Anita one afternoon. Anita was there to do meal preparation, as well as other domestic tasks including the laundry. She arrived five minutes late, but then was immediately working, preparing several dishes with Sally, as well as helping out with some other jobs. And she stayed. A couple of times, as Anita worked on past her rostered time, Sally said, *"Time you weren't here, isn't it?"*. When I asked Sally later about Anita having stayed over her rostered time, Sally said, *"Yes—I mean they often give me an extra ten minutes or so. I don't know why but they do, you know, stay back and give us a hand"*. In the session I was asking Sally about, Anita had stayed two hours after the rostered time, and reported that this was not uncommon. When Joanna told her coordinator that she *"found it quite difficult to do everything that I needed to do in the time that was given to me"*, the coordinator *"turned round to me and she said, 'You're doing too much' [...] 'All you have to do, is go there and do that job. Don't get involved about doing anything else'"*. But Joanna was *"sure they know [extra work] is going on. But until it falls over, they'll just keep on closing their eyes to it"*. Leaving clients' needs unmet both undermined their presentation of self, and placed workers' sense of competence at risk.

Studies have repeatedly found that workers work unpaid time. For example, 13 per cent of Australian DSWs (Martin & Healy, 2010, p. 118), and 45.5 per cent of CCWs (Martin & King, 2008, p. 111) were doing so.⁵¹ A recent UK study (Rubery et al., 2015) described several ways in which workers worked unpaid, as well as their motivations (Hebson, Rubery, & Grimshaw, 2015).

⁵¹ More recent unpaid hours data was collected by King et al. (2012b) but was not reported in the government publication. Stone (1999, p. 66) suggested that organisations and bureaucracies have been "betting that the caregivers will dip into the well of their own humanity to offset the budget constraints and the stifling rulebooks".

Advocacy

Witnessing poor conditions for clients drove workers like Stella, Anita, Tash, Vic and Joanna to “*go in and bat*” as Anita put it. Advocating is frowned upon by most provider organisations; they argue that there are independent advocates available. There is also a risk of conflicts of interest developing: for instance, a worker may advocate for something, and then be the ‘beneficiary’ of any additional hours of work generated. While they understood this reasoning, some workers were incensed by the lack of trust it implied.

Most workers believed clients or residents needed more assistance than they were receiving. “*Because you, you have that feeling with most clients that you go to, that [speaking quietly] you want to make it better. You want to make life a bit better for them, you know?*” (Anita). When she asked for extra support for clients, case managers’ responses like, “*“Anita, we’re just over. If I go with that, I’m just going to get my arse kicked, because we’re well and truly over hours. There’s just nothing”* were “*the hardest thing to hear*”. She thought: “*There’s always fucking something [said adamantly and loudly] you can do—there’s always something that’s got to be able to be done*”. Workers compensated by, “*just popping in*”, for example, saying “*‘Just called for a cuppa. D’you want to go out in the garden for a bit?’ You know*” (Anita). The many examples workers gave of clients’ unmet needs did not seem to be of trivial or ‘luxury’ needs, but were central to the continuing wellbeing of the client.

In facilities, missed details or unfinished tasks could fairly readily be left to those on the next shift and extras were small scale. In the community, sole workers witnessed clients’ capacity or failure to manage. All expressed a sense of responsibility to do a satisfactory job, and knew that other assistance was not coming. The presentation of self that was apparent in their overt comments about themselves was manifest here too. Workers wanted “*to make life a bit better*

for them” (Anita). Their sense of efficacy and worth was reliant on being able to make that difference.

Organisations and self-care

Organisations had policies intended to minimise burnout, keep control over expenses, and curtail emotional ‘over’-investment. The standard provider solution to emotional exhaustion, for example, was *“Don’t get involved with the clients. Leave it behind!” (Anita).*

When workers—worried about people being left in un-changed incontinence pads (and soaked clothes) all day, for example—reported their concerns, case managers might say they would attend to the need, but workers often repeated their requests several times without result. As Anita put it, *“you leave it for a couple of weeks, and you go back, and ‘It hasn’t really been the right time’ [...] I feel that [the case manager’s] letting my side down a little bit by doing that”*. Workers understood that organisations had to manage on tight budgets and that for some clients the assessed package was already completely taken up, but they also felt the lack of responsiveness was a sign of how much organisations valued—and, I argue, trusted—them. Did provider organisations think workers were sufficiently trustworthy to be sent into people’s homes, to manage medications or other matters of personal well-being, but that their reports about clients’ needs were not trustworthy? To Joanna, this meant *“There’s no respect. There is no respect for us from a lot of people”*.

Summary—Workers’ performances

Most workers understood their role as working on clients’ and residents’ presentation of a congruent self. Routines of washing, shaving, dressing, and meal preparation and eating were intended to mirror clients’ historical lives, or to create versions of ordinary lives. Practice also allowed workers to show expertise, reinforce clients’ capacities and, in these performances, present their

own competent selves. Thus, practice had a dual outcome: when workers were effective in sustaining clients' presentation of a competent self, their own presentation of self—as effective, compassionate workers—was enabled.

Workers' presentation of a competent self could be compromised by external signals of mistrust, or of low value, and by being unable to feel competent in their work for their own and clients' presentation of self. Boundary crossing can thus be seen as a compensatory mechanism. Further, there is evidence from the present study that organisations knew what was going on and ignored it; they can, after all, more readily make ends meet if clients can be supported with fewer paid hours, thus gaining some competitive advantage. Martin and King (2008) posit that organisations are using workers' generosity to "fill gaps and manage the workload" (p. 118). But there are risks in workers' apparent generosity. As well as working without insurance, workers might be late for subsequent clients (and see Rubery et al., 2015), promote unfair comparisons with workers who do not bend the rules, and create inequities between 'attractive' clients and others. Further, in policy terms, it means that there is no real calculus of how many hours are required to meet the needs of people with disabilities.

Theme 3. How workers talk about clients

The ultimate behavioral materials are the glances, gestures, positionings, and verbal statements that people continuously feed into the situation, whether intended or not. These are the external signs of orientation and involvement—states of mind and body not ordinarily examined with respect to their social organization. (Goffman, 1967, p. 2)

Workers talked about the people they work with. These "verbal statements" about the clients are reported here. Some verbal statements were expressions of solidarity and enabling attitudes, while others demonstrated resentful and disabling perspectives.

Resentment and othering: Disabling verbal statements

Some workers seemed to find work unsatisfying and many clients either annoying or unpleasant. Tilda represented the extreme end of this resentful, and disabling, attitude to clients and residents. In interviews, she was frequently very negative about many aspects of her work and about clients, but repeatedly told me about ways in which she demonstrated care. This split performance was most evident when, after a conversation in which she had sometimes been negative had concluded and I had turned off the recorder, she became quite emotional about the work: *“‘I love what I do,’ she said. She spoke from the heart about this love. And she spoke about hating that their work was so negatively seen—she talked about this for a minute or so”* (Fieldnotes).

In the community, her interactions with Kostas, a man whose first language was not English, sounded like a battle (see Chapter 7), with him wishing to be at least somewhat independent and her resisting. She portrayed him as deliberately difficult. At Shore View, she was deeply discomfited by residents' sexuality,⁵² and made remarks about their social or moral status. As well as making several critical allusions to the sexual history of one female resident, she remarked on semen smells, she was forthright about her abhorrence for *“cleaning pooh off testicles”*, and the rationality of castrating male residents, saying *“they don’t need [their testicles]”*. These attitudes affected her practice. She reported responding to men masturbating in ways that humiliated the men and embarrassed other staff. This was only one example of her disabling practices.

⁵² Responses to the sexual lives of people living in residential facilities are receiving increasing research interest (see, for example, R. D. Brown & Pirtle, 2008; Hamilton, 2008, 2009; Hollomotz, 2008; A. King & Cronin, 2013; McAuliffe, Bauer, Fetherstonhaugh, & Chenco, 2015; Murray & Minnes, 1994; Shuttleworth, Russell, Weerakoon, & Dune, 2010).

Us and them

Tash, Tilda and to a lesser extent Blanche made dismissive or de-personalising remarks about clients and residents. Tash, for example, wanted to advocate, to give residents a voice, yet used the impersonal pronoun, never referring to residents by name. It was “*the people*”, “*they*” or “*them*”, or “*the clients*”. She said she would miss “*the people*” were she to leave Harvest, but also complained about them. While “*clients*” helped with some small jobs, “*the rest of the time [what] we’re doing is running around being little housemaids*”. This sense of inequality was ever-present. For instance, she commented that they “*get to do so much more than the everyday person*”. Further, she, Tilda and Blanche seemed to believe that some residents or clients did not deserve support—or the amount of support they had. Blanche, for example, talked about a client who required strict procedures to be followed to prevent a worsening of her condition. But Blanche thought “*it’s all just in her head, [...] Poor thing*”.

These three workers were attached to clients or residents yet at the same time resentful. They felt pushed around and displayed this in their comments. They also seemed to feel that they had less access to resources and opportunities than some clients. It appeared that their presentation of self relied partly on maintaining the fragile and readily permeable boundary between the clients and themselves. They did this with overt resentment, othering and disabling interactions. Others, like Stella, did so with (misplaced) kindness, and pity.

Sympathy and pity

The empathy that I noted in my diary after meeting Stella veered into sympathy and pity when she talked about clients’ financial situations or perceived isolation. Asked whether the work had changed her, she talked about her need to build a financial buffer against the sort of lives some of her clients had. Sympathy and pity permeated the slightly strained exchanges I observed

between her and Raphael. Perhaps he was aware of her view of him as a sad figure:

I was holding myself together during my first visit and then went out to the car and just burst into tears, 'cause I just thought it was so sad. I just thought [Raphael's] life was so sad. Mmm. At the age that he was at, and yeah. And I could sense this loneliness as well.

She also thought he was resisting the limitations imposed by his illness; he was not “*the victim of the disease just yet*”. Terms like ‘victim’ imply a status which—while being resisted by Raphael—seemed to Stella to be imminently applicable. Blanche, too, felt “*sorry for*” several clients who—as she saw it—“*had nobody*”. That workers “*might be the only contact they have*” (Stella)⁵³ affected the interactions between workers and clients, and was driving some unpaid work. For these workers, the line between empathy, sympathy and pity was not clearly drawn. The feelings they expressed were potentially disabling: clients were not positioned as people with agency or lives of their own (however unfamiliar), but as people in need.

Between disabling and enabling: Statements of separation and difference

Sometimes concern and sympathy were linked with a somewhat evangelical admiration for clients, which again positioned the client as in need. Ruby, for example, appeared to view her role as adding value to otherwise compromised lives. There was additional energy in her voice when she talked about activities that freed people from some of the physical restrictions they experienced. Swimming, for example, “*is about getting out of that*”. In the water, “*they’ve got this freedom that, um, just is magical. It’s really quite awesome to see [...] when they get in the water you can just see [now, she was really engaged again] yeah, that they’re*

⁵³ See Productivity Commission (2011c, pp. 113-114).

having a great time". These ambitions risked positioning the people they worked with as cases. Client and worker remained separate and different.

Together and sharing: Enabling verbal statements

On the enabling end of the continuum were workers' verbal statements that demonstrated solidarity with clients and residents. Anita's expressions of intense sympathy for clients were accompanied by a sense that 'we're in this together', and a matter of fact approach to limitations. Thus, she spoke of old age as being "*really, really hard*", of Sally being "*painful sometimes. She can be sad [voice dropped]; she can be depressed*" — "*she can be all the emotions I can be*". There were conversations and laughter while a client sat on the toilet: "*She was one of the funniest people that you could [...] she could have a pooh and you could have a conversation at the same time*". This way of thinking about clients and residents was truthful — and unafraid and unashamed — about being human.

The sense of solidarity workers in this category expressed about clients' situations was powerful. Brian and several others used the phrase, "*There but for the grace of God go I*" for their approach. There was solidarity, too, in Vic's description of those clients with acquired disabilities as "*unlucky*" to have had their accidents; Pete, for example, had "*really hurt and banged his head and he was just a bit — a little bit forgetful*". Vic's sense of fellow feeling was apparent when he told me about working with Ellie on the night her boyfriend dumped her (see Banks, 2016). She was: "*Upset? Yeah, yeah — absolutely*". "*Oh yeah. I felt so bad for her. She — I could imagine; that's a horrible situation. It's a horrible situation, but it's part of life, unfortunately*".

There was no othering in these discourses. Workers used "*we*" not "*they*". Client and workers were in it together, collaborating.

Connecting

Collaborating and connecting were central to the way Anita, Brian, Edwina, Jai, Joanna, Shirley, Vic and Miriam talked about clients and residents. That Vic was—and felt good when—with the residents or other clients was apparent in all our conversations. He liked working on night shifts in his aged care job, because there was time to make connections with people. These workers relished opportunities for engagement. Many of them told me that they liked *“older people. I have a great respect for them”*. *“I mean, the one lady in St Kilda is 94 [...] So you can imagine how many stories she would tell me, And I just love that!”* (Joanna). Jai wanted to *“understand my, like, that person, as an individual—and their life—as much as I can”*. *“You’ve got to be there; it’s there and then... It’s in their shoes, there and then”* (Miriam).⁵⁴ Understanding the individual was part of learning how to best maintain clients’ independence and sense of self.

Whole and enabled

Overwhelmingly in interviews and when I saw him interact with current and former clients, Brian’s guiding principle was that regardless of diagnosis or impairment, the person was present and valuable. He focused on their assets and capacity. He told me about visiting a man with fairly advanced dementia:

So I went along and met him: hell of a nice fella. And, I suddenly look round his house, and there’s a sticky note saying ‘this is the fridge’, and ‘your lunch is in the fridge’ [mimes opening the fridge door], ‘this is your lunch’, ‘this is a toaster’, and I ... was just sort of looking around and I said, ‘So, how’re you getting on, mate?’ And he said, ‘Oh, not bad. Want a cuppa?’ I said ‘Yeah’. So ignoring his sticky notes, he went along and, ‘How many sugars?’, ‘Just one’. Made me a drink and

⁵⁴ Miriam also made a distinction, saying *“Yeah—doesn’t matter what culture they’re from; they have—but they’re still individuals in their culture! Just because they’re an Aborigine doesn’t mean that they need the same as the other Aboriginal person”*.

*we're sitting down having a chat and I'm still looking at all these notes and thinking to myself, what's going on here?*⁵⁵

Mechanisms like the possibly clumsy sticky notes were intended to enable a continued performance. Workers understood the need to provide the context so things “*make sense*” (Leonie) for clients, but they opposed “*trying to wrap people up in cottonwool. Oh this has happened to them. And we mustn't let anything else happen to them. So they're actually not allowed to live life*” (Leonie). Several workers expressed similar attitudes to such marginalisation, and were angry when clients or residents were treated with disrespect. Edwina, Brian and Vic gave examples of being out with clients who were ignored in social interactions.

These workers watched their language. Leonie didn't “*like the word 'sufferer', 'victim', and I'm quite pedantic: I'll pull people up on that*”. They also rejected the diagnosis-driven assessment and ‘management’ of clients and residents, saying it put people into “*a category—they're not classed as individuals anymore*” (Miriam)—and ‘pigeon-holed’ them. They rarely mentioned the impairments people were living with, and instead celebrated individuality and capacity, and clients’ presentation of internally congruent selves. When Leonie told me about a facility resident who had stood up against poor treatment, she said, “*See, I love that. I love it when people find that, um, you know, that power to kind of express themselves, and who they are!*”.

Conclusions

How workers think about, perceive or speak about the people with disabilities with whom they work affects practice and meaning, and shapes their work for clients’ presentation of self. Their verbal statements could be illustrated arrayed on a continuum. At one end would be expressions of resentment and disabling attitudes. Here, as Dobbs et al. (2008) found, clients and residents were placed

⁵⁵ The client may benefit from prompts sometimes.

in categories of otherness where they may experience “status loss and discrimination” (p. 517). At the other end of the continuum were the inclusive, ‘it all happens to us’ view and a desire for connection. Here, workers tended to speak in terms of what people could do, not what they could not. They were realistic and recognised, or worked for, solidarity with clients and residents. Workers were seeking ways to both present their own competence and compassion, and—at best—ensure that clients and residents’ presentation was also congruent and competent. Techniques used by workers when engaging in presentation of self included citing evidence of compassion and competence, and comparing themselves with failing colleagues. It was apparent, though, that workers were frequently disempowered, lacked the capacity (or right) to affect practice, were only sometimes able to gain better outcomes for their clients in ways which were not at their own cost, and were often treated poorly by employers. Workers expressed resentment that—most often—was directed at employers or colleagues, but sometimes spilled over to clients.

How workers spoke about clients again displayed the self. Sometimes, this added weight to their performance of empathy or competence; sometimes it hinted at anger or discomfort. For many, evidence of the leakiness, frailties and idiosyncrasies of clients seemed to present an opportunity for sharing, connection and solidarity; for other workers, it sparked fear, shame or revulsion and this played out in pity, resentment, and humiliation of clients. The risks and traumas of residential or community aged care and disability support, so often depicted in the media, were indeed present; what the media missed was the solidarity, the shared experience of being a flawed human that care and support work provide.

Care and support provision involves a relationship. Thus, the client shapes workers’ perspectives and actions. The next chapter (Chapter 6) is devoted to clients’ presentation of self, performances, and their attitudes to workers. In

Chapter 7, the interaction between workers and clients is reported on, before, in the final chapter, a model is proposed describing the relationship between the themes, along with areas for further research and policy development, and the study's limitations, and I return to the research questions and ways in which meaning is created in the delivery of aged care and disability support.

Chapter 6.

Findings: Working to accept care and support

Then I realised afterwards, you know, you're supposed to be downtrodden. You know I, I can't comfortably do that. But that's, that's what you're supposed to do, and some people I guess are quite adept at it. It's how the system works. (Olivia)

Introduction

Olivia suspected the care and support 'system' worked by having clients accept—or even become adept at performing—an incompetent and downtrodden self. As the analysis reported in Chapter 5 showed, her suspicion was borne out by some workers' reports of practices and attitudes that perpetuated the disabling and demeaning of clients. But most clients were, like Olivia, working against being downtrodden and othered, and resisting adopting the 'sick role' (Parsons, 1951, 1975). They did a great deal of impression management, both in their overt 'presentation of self', and in the work they did before and during support interactions. Here, where the presence of support risked exposing clients' expectations or assumptions about themselves, their 'verbal statements' (Goffman, 1967) presented identities that were distinct from 'client'. In this, they drew on stories from their past, skills they retained and similarities to competent others. And they, as had the workers, sought ways to create the 'proper state of mind' in themselves and in workers that would enable the presentation of their chosen self.

Such performances required agency. Sometimes clients displayed such agency by rejecting workers or supports that could undermine their presentation. This resistance was evident too in their staunch criticisms of provider organisations.

Following the same overarching analytical themes, Presentation of self, Performance, and How participants spoke about one another, this chapter is devoted to clients' presentation of self, their performances, and how they talked about workers.

Theme 1. Clients' presentation of self

'Client' was not a prominent part of participants' presentation of self. Clients were working against a public image as 'victims' (see Chapter 4), 'downtrodden', mendicant or incapable. In their conversations with me, they presented selves that were competent and capable. They were effective operators, and ethical and decent people, with particular skills or expertise. This performance was, though, sometimes compromised by workers and organisations, and by factors—abuse, poverty or isolation—that were beyond their control. The precarious nature of life with an impairment was apparent; clients spoke of managing, resisting or rejecting physical difficulties.

Clients presenting a competent, independent and capable self

Clients often told stories about the expertise they had in their working lives. Thus, Bill talked about managing workforces, about teaching (including helping Brian learn some mathematics) and about belonging *"to every bloody thing"* in the small communities where he had lived. As he put it, *"Yeah, well, if you have a bit of a social conscience, you finish up in everything"*. He presented his professional expertise when he talked about provider organisations and the *"side-effects"* of poor organisational practice, *"which don't affect me personally, but they do as a professional. Because I see what happens to an enterprise when people start mucking about with the lowest of the low—underpaying them"*.

Nicko, Evelyn, Sally, Winifred, Norah, and Raphael, too, talked about the particular skill sets they had developed. Nicko, for example, often returned to his passion—trees and timber—and to his sense of himself as *“adventurous”*: *“in the back of my mind, I am a tree man”*. He showed that his expertise was still valued, telling me about people approaching him for expert advice. A few times he asked me if I had any knowledge of that sort and when I replied that it was limited, he explained aspects of the craft to me with great enthusiasm. Nicko showed me his home gym. Its walls were covered with framed photos of him being presented with awards, at exhibitions with well-known timber craftspeople, and in his safety gear standing at the base of apparently enormous trees. As well, there were slices of timber, beautifully finished, alongside his exercise gear. Since his accident he had been steadily working his way back into his old craft. Visits to the art school were part of that, as were fieldtrips he had taken with foresters and conservationists: *“down the South West—right—supporting the kids; I’m the safety officer”*.

In these conversations, and those with most other clients, participants were keen for me to know about their careers and the skills that remained useful. They seemed almost to be showing off to me—sometimes at a cost to workers. Evelyn, for example, used her knowledge of grammar and language as a common thread between us, and one that somewhat excluded Blanche.

The many stories clients told me about their skills and strengths seemed part of a presentation to counter negative constructions of people receiving support. They were showing me that labels of ‘client’ or ‘recipient’ were not the sum of who they were. How support was delivered, though, could undermine this presentation, as could having to ask for help. Norah, who had a successful professional career, found her recent increased reliance on others very hard. She disliked having to ask for help, and was disheartened by support that was careless, incompetent or humiliating. That these circumstances put her

competence and value at risk was demonstrated during one of our conversations. We were talking about aspects of the support she received in Cliveden. Norah was fairly critical of some practices and people and her tone was both resigned and annoyed. But then the telephone rang, and Norah answered it. It was one of her children. I left the room. When the sound of talking had stopped, I knocked and went back in. Norah's mood had changed. She recounted to me several aspects of the call—about how well this particular child was doing, and some advice she had offered about grandchildren. We returned to our earlier conversation. Her tone had changed: *"most of [the staff], the majority of them are very good; no, I think they're all good. They'll all, they'll all help you. No, they're all good—calling for them. Really. I can't complain about that at all"*.

Clients' identity by comparison

Like the workers, clients presented self through comparisons with others—clients (or how they imagined other clients to be) and workers. Presentation was as somewhat independent, and more independent than many others. Several told me, as Sally did, that they were *"fairly straightforward; I'd be one of their easier—they don't have to lift me or do anything dramatic with me"*. Norah thought more experienced workers were assigned *"to some of the ones who can't do anything for themselves"*. She, on the other hand, was *"vaguely able to do for [herself]"*, and so was *"left a bit to do things for [herself]"*. Evelyn (and Blanche) performed a short, jokey routine when the phrase 'frail elderly' was mentioned, hunching over, curling their fingers and shakily grasping the edge of the table. Despite having had a support package for several years, Evelyn said she was *"not as decrepit as ..."*, and wondered, *"do I fit in the mould of a recipient of a package?"*.

In these remarks, clients presented selves with capacity. Olivia described Joanna as someone who *"matches my efficiency. She matches, she can follow my*

thinking". Olivia was also physically fast. When I observed her and Joanna, the pair were so fast in the shops that, when I stopped to make a note in my diary, I had sometimes to run to catch up to sight distance. Olivia laughed about this later, remarking *"I know. I've flummoxed the rest of them!"*.

Perhaps reacting against public discourses about undeserving welfare recipients, several people in the study displayed ethical and socially responsible selves. Here, they compared themselves with support workers. Laurence described himself as *"very fair"*. He rejected workers only *"for extremely good reasons"*, including that *"one of them tried to, um, to slander my other support workers"*. Evelyn was perturbed when a worker asked her about Ann-Marie, telling me she thought *"That's not fair, telling one support worker about another; that's not fair. That's not ethical"*. And Raphael wanted people around him to be ethical: *"If you tell me something, I'll remember it. And I'll ask you about it later—to test your veracity—to see if you are telling me the truth"*. Bill's social conscience was evident in his comments about workers and provider organisations, as well as in his stories about volunteering. He argued that if he were to be *"quiet [with organisations and ineffective or dishonest workers] [...] they'll walk all over you"*. Nor was Olivia prepared to accept things that disturbed or belittled her; she wanted to be treated as competent and with professionalism, and gave examples of care and support workers' rudeness or incompetence. Bill and Olivia thought they *"deserve better than that"*, but each suspected that they were *"beginning to get a name as a person who finds things wrong with people, or is a complainer, or whatever"* (Olivia). Complaining is a means to seek redress for things which are within the control of individuals or organisations, and to resist or recover from demeaning interactions.

Another strategy clients used was to compare themselves with me, seeking commonality not difference. This happened a lot. Erica and I talked about cooking. When I commented, *"I don't want to cook every day"*, she responded,

"Yeah—I'm the same as you". She used the phrase "I'm with you" about several other things in our conversation. Though Gerry was less voluble than Erica, he too spoke about cultural common ground, including music, and smiled when he identified ("these are Subway [café] bikkies") where the biscuits I had brought for morning tea came from. Evelyn mentioned some music, saying it was "quite a long piece. You know it, don't you?". She and Laurence showed me their research skills. Laurence, giving me a document he had been working on, said "you'll get to know me, Susan, because I do my research. I love research [and] I'm well aware, with my eyes wide open about what is what and who is who". Three clients lent me books about shared interests.⁵⁶ This seeking of common ground may have been a way to distance themselves from constructions as failing or dependent.

This precarious life—managing, resisting or rejecting difficulties

For some, the illnesses and impairments they experienced were simply things to be managed; others spoke of prevailing and still others of resisting these bodily experiences. In all these modes, presentations of self were being honed.

Norah, Winifred, Cornelia and Bill managed—they came from the *"mustn't complain"*, or *"as well as might be expected"* generation. Sometimes they were in pain, and some parts did not function as they would like. Winifred's descriptions of herself, given with a laugh, reflect their responses. She said she was quite *"fragile"*—*"Cause I'm very weak at this stage"*, despite looking *"so well, you know! Lady of leisure!"*. Sitting quietly, she was *"wonderful! I, I don't even have pain at the moment. It's only when I stand up—my back doesn't support me"*. She had a stick and a walker, but stayed indoors *"unless someone is with me. I get dizzy"*. She and Norah both had *"awful"* days, when they were *"just not well, and so tired. It's this terrible tiredness that comes over me. I don't know whether I do*

⁵⁶ I accepted no gifts from participants; book loaned were returned quickly, with a note of thanks.

something a little bit too much ... No, it's just your age dear [laughs; S laughs]"
(Winifred). Bill's knees were *"worn out, I had one replaced [but] came out of the hospital with a Staph infection in my face, and a bladder infection from the catheter"*. But these things were to be expected *"when you're ninety"*. Like Winifred, he treated changes in capacity with dry humour. He talked about the 'benefit' of being less well: they *"then issued me with what's called a white [benefit] card [...]"* And then I had a stroke. And I crossed over from the white card to the gold card [smirking]"

Cornelia, Olivia and Evelyn managed in other ways, expressing pride in the ways in which they prevailed over difficulties. Cornelia told me that *"her shoulders are terrible—partly the result of a flat-on-her-back fall last year"* (Fieldnotes). To this, she added that her right hand was not functioning, and that while waiting for cataract surgery, she had a retinal haemorrhage, which had left a dead patch in the retina. Yet a conversation we later had implied that her needs for assistance were very slight, and included her delight at having *"worked out—it's very funny, really—I worked out the other day, how I can get my back dry"*. Prevailing over her shoulder injury, she *"decided to get a very big towel, throw it over the chair and sit in it [laughing] and [Cornelia moves her shoulders from side to side—squirming]"* (Fieldnotes). Evelyn enthusiastically reported the numerous conditions which affected her. Each time we spoke (five times), she referred to her medical history. These experiences were clearly part of her identity, and evidence of her resilience.

Sally was resisting, though with significant effort. Her recent acquisition of her kitten, Olaf, brought both delight and difficulty. Some friends saw Olaf as giving Sally *"a new lease of life"*; she agreed: *"I think it has. Oh, she's my free entertainment"*. But Sally was depressed by the decline in her health and capacity and by others' construction of her as vulnerable. One friend had criticised her purchase of Olaf, *"'cause I'm old and in a wheelchair... So, you know I*

shouldn't have and I'll end up killing the cat. I cried; I was so upset". Sally's description of herself as an "easy" client was—at least in some ways—patently not true. As both she and Anita pointed out, Sally was effectively hanging on to her independent life 'by one hand'; should she even temporarily lose the use of that hand, she would be unable to operate her wheelchair, feed herself, use the telephone or other household equipment, or do any personal care. As well, she had poor "circulation in this leg, and I've been really cold around my knees", and her "fingers are sort—I think it might be arthritis. I've got a bit of a lump there, and that's not normal for me". When we last met, she told me: "I'm in bad renal failure. Mmm—I had a day in hospital last week, and they did some bloods, and they weren't so good. It is a bugger". The incremental loss of health and capacity Sally was experiencing was "a real shit" (Sally). Erica's dream of moving out of the group house and into her own unit was potentially compromised by epileptic seizures, which were "terrible. And they go on for a long time sometimes [...] and I can't do very much. [Erica sounds sad]". If they continued, she "probably won't [go into her own unit]—I'll probably stay here". All such conditions threatened participants' independence.

Norah had been receiving support while still at home, but had moved into Cliveden almost two years before we met. In some ways, this was an improvement because *"I can ring and somebody will come and do those things for me, which you can't do at home. Mmm. So that's a big help"*. But she was resisting. Being able to ask for help was only useful *"if you do it! [laughs] But I don't, I hate doing it, so I struggle along by myself. Which is probably stupid, but I'm sure a lot of people feel like that"*. She wanted to *"feel less, less dependent"*. *"[T]he hardest thing is to lose our independence at this stage. And have to ask for things. It's the most difficult thing I've ever done"*. Norah's career had been high status and reliant on efficient systems. At work, she had known *"how to get what you want"*. Now, she hated being unable to affect how the larger system of the facility worked and

sometimes, *“if it gets too hard, you give up. Let things happen the way they see it should happen—which is not right. Makes [...] you lose your independence even more. And that’s the worst part of being here, for me”*. Such reports signal clients’ sadness or the depression Laurence had mentioned. For him there was a risk of going *“too far down; it’s like, I’ve got to get myself back up. I mean it’s a long way up, a long way up there to get back up”*.

Resisting being ‘placed’: “I’m not heading for a nursing home yet”

For all clients in the community, ‘placement’ in a residential facility loomed as a possibility. With the exception of Cornelia, they resisted what they saw as a public admission of incapacity: a failure in their presentation of a competent self.⁵⁷ Only Cornelia would *“rather be—ultimately—in a nursing home where they’ve got somebody on call all the time”* if her health declined.

Bill, who was 90 years old at the start of the study, expressed the more typical view. He had talked with other people:

about, um, rellies they’ve got in homes—I’ve seen some of them. And they’re, somebody said they’re God’s waiting room. Well, that’s the way they look, too. The people are lined up round the outside walls, and I’ve had so many people who say, you know, “I’ll die first, before we go ...”. And I can understand why!

Bill lived in his family home with his wife Delia, and their adult children visited regularly. Gerry and Erica lived in a group house. All other client participants resembled Cornelia—they lived alone, and most had no family nearby. But, all were unhappy at the prospect of living in a facility. As Raphael put it: *“Once I fall, I’m finished. Once I fall, and I break something, I’m headed for a nursing home. And I’m not heading for a nursing home yet”*. The prospect also alarmed Nicko, who had narrowly avoided being admitted to a nursing home as a young man. The possibility was *“disgusting [...] I mean it wouldn’t be any place for me, would*

⁵⁷ Fear of placement has been argued to result in poor outcomes for people who might receive more appropriate care and support in a residential facility (Söderberg et al., 2013).

it?”. Living independently was a kind of badge of honour—*“I’ve learned to live on my own—and so I’m happy”*. Most clients wanted to be *“carried out of here in a box”* (Evelyn).

Two people did enter residential facilities during the study, both because an injury prevented them from using their hands. That an apparently small change in status—like a hand or wrist injury—could mean the difference between living in their own home or in a residential facility demonstrates the tenuous nature of independence.

Agency and life chances

In general, the self-selection process meant that client participants were well-educated, middle-class people, many of whom had been successful in work. But the safety net of historical life chances was somewhat flimsy. Three people, for example, told me about serious physical or sexual abuse they had experienced at the hands of family or support workers, traumas that had made them wary of male staff.

Several people made it clear that they were very careful with their money. Sally spoke of having *“too many overheads”*; *“I get paid tomorrow, thank god. I’ve got a dollar ten in my purse. Oh it is every bloody week! And I thought, I dropped medical benefits, the rent went down and I still haven’t got any money”*. I watched as she and Anita prepared meals for the week. They talked about ingredients, ruling some out because of the expense, and working out cheaper substitutes. Flipping through a recipe book, Sally said, *“I’m not going to pay \$9:50 when I can get it for \$7. Home-made fish and chips, [...] Oh, here’s lamb shanks with carrots, chick peas, potatoes—that’d be nice. But you can’t afford to buy the bloody lamb shanks!”*. When Olivia went shopping, with Joanna or Blanche, she was careful to keep an accurate accounting of each item, setting herself a limit and making sure to

remain within it. Her carefulness annoyed one worker (Blanche), and delighted the other (Joanna).

Pets were an often expensive necessity for some participants (Evelyn, Sally and Olivia). But pets provided companionship. Human companionship was harder to access. Evelyn said that having domestic support was good, but social contact was better. She had *“finally convinced Blanche—it’s taken a while—and also Joanna, that part of their help to me and backup, is to sit and have a cup of tea and talk. Or else, listen to me talk, ...”*. How workers behaved could exacerbate some clients’ sense of isolation. As well as workers being *“the only people I see some days”*, Raphael described the social aspects of Stella’s visits as *“sort of socialising—sort of”*, and the two people who visited on another day had only the most cursory and instrumental of conversations with him as they delivered his medication and then oversaw his taking it, respectively. A few workers might, Raphael said, *“do the work for you, but don’t be surprised if [they] leave fifteen minutes early”*. I asked him if this was because they were *“catching up on other jobs”*, or not wanting to *“invade his space”*. He thought these were unlikely causes, saying that one *“doesn’t want to spend too much time with me”*. Maintaining a sense of competence and likability was hard in these circumstances.

Presentations of competence could be sustained by rejection of the sick role. Olivia vehemently refused the sick role, noting that *“according to the conditions I have, and my age and the fact that I’m a woman, this deems me 75% something for this thing and that thing”*, but *“I’m kind of in charge here, so ... [laughs]”*. Demonstrating that they were in charge was part of the impression management clients did. While accepting or indeed happily taking on the sick role may be an empowering act (and here see work on the ‘cloak of incompetence’ by McLuhan, Pawluch, Shaffir, & Haas, 2014), this was rarely apparent amongst the study clients. Olivia and many others commented on the

conditions they were experiencing only to talk about how they were overcoming them or adjusting how they thought about them. Such resistance was *“confronting for service providers; they are more used to people who do play the sick role, and who will perform to get additional services”* (Olivia, Fieldnotes). She saw moving to a consumer-directed care package as a chance to escape some of these expectations and arrange some things that *“will truly make me better”*. She worked at re-shaping some aspects of daily life, including walking *“very slowly”* to a local supermarket for her groceries, rather than being driven there. These changes would, she hoped, *“make me more independent because it will lead to achieve the point where I don’t have any dependence any more, except financial”*. *“I’m a person who doesn’t like to be helped”*. Nicko, too, had worked to regain a great deal of capacity, and attributed this to the fact that he has *“always been a competitive person—in what I do. I have a go, you know?”*; it was the *“reason why I’m walking”*. Nicko laughed a lot. He said, *“Well, [that] was my life once. And it’s coming back—some of it is coming back”*. That he had been *“as useless as a pair of tits on a bull—excuse my French, but it’s true”* added to his pride in his steadily increasing capability. Now, he forgot *“half the time that I have a disability”*. Increasing independence also drove Erica who was pleased that she had recently learned to catch the bus to work: *“Someone had to go with me, except no one goes with me any more. I know what time, and I go myself!”*.

Cracks in the presentation of a congruent self

Performances of competence were not secure. Bill and Raphael were sometimes self-deprecating, demonstrating confidence in their own (intellectual) competence. Such joking self-deprecation was rare in the interviews or observations with Evelyn, Laurence and Erica who sometimes made remarks that reflected anxiety about competence. Erica was self-critical, commenting that she did not *“know how to look after a garden. Every time I look after it I always ruins something”*. She also said she was *“bad at”* some household tasks. Only she,

Evelyn and Laurence commented on receiving the overt approval of support workers, and all three often seemed to lack confidence. The self-deprecating comments Evelyn and Erica made reflected the critical comments other people had made to them. These three participants were less secure in their performance of self as competent and ‘acceptable’.

Summary

In their remarks about themselves and others, most clients seemed to want to stress that ideas of vulnerability or incapacity did not apply to them. All sought ways to counter these constructions with demonstrations or evidence of their skills and agency. This was particularly evident when the telephone call reinstated Norah’s identity as valued mother and grandmother and altered how she spoke about Cliveden.

This finding parallels that of Clancy, Balteskard, Perander and Mahler’s (2015) study. There, participants did not dwell on the falls they were asked about, but instead drew on life histories that characterised them as courageous and optimistic. The men “became animated” (2015, p. 7 of 10), sharing aspects of their life history that showed “who they were through their physical strength and prowess” (p. 7 of 10). Women in the study “struggled on”, with a “grin and bear it” attitude. For all, the falls they had experienced “had no bearing on who they were or wanted to be seen as” (p. 7 of 10). When Nicko drew on stories from his adventurous past, or Olivia spoke of her activism, Erica of catching the bus to work, Winifred of her business acumen and Raphael of his skill with people’s emotions, they too were showing the skills and capacities they had, presenting competent selves both to me and to workers—and contradicting their client status.

The presence of support risked undermining clients’ expectations or assumptions about themselves; when it was effective, it enabled them to

maintain their competent self. Their focus, though, was on identities that were distinct from 'client'. But clients—as well as workers—were doing a great deal of work for this maintenance.

Theme 2. Clients' performance

As the analysis of first interviews progressed, I saw more and more evidence of the work clients were doing. Clients worked to make receiving support easier. They performed physical or instrumental tasks, bureaucratic tasks, and intrinsic or emotional tasks.

Instrumental tasks

Some clients perform the clichéd tidy up before the worker arrives, or set out things to make the service encounter more efficient. They wrote shopping lists, got in supplies of a particular product, did a rough sort of the dirty laundry, or worked at composing their clothing.

Olivia did things *“before to make it so that she will get more done [...] I'll wash my dishes, because that'll mean she takes less time doing them and she doesn't put them in the wrong place [laughing]”*. Evelyn had an arrangement where she would perform one of the workers' usual tasks in exchange for asking them to do something extra. Bill's wife, Delia, did many of the tasks for which workers were sent: vacuuming and dusting as well as the laundering and washing up. While doing tasks before and during visits made it easier (usually) for workers to deliver support, it also maintained clients' presentation of a capable self.

Most clients planned what the worker would do during the visit. Thus, Cornelia would *“give Tammy a few directions; I will say, “I think the microwave needs doing this week, you didn't do it last time”, or “I think that the vegetable bin at the bottom of the refrigerator needs cleaning out”*. She, Olivia, Sally, Winifred and

Evelyn made lists and discussed them with the worker, negotiating what would take priority.

Most had done *“a bit of reorganisation”* to make assistance more straightforward. Cornelia was not *“scared of having someone come in”*; it did not *“worry me particularly”*, but she did *“have to think about my, my way of doing things [...] I have to reorganise my life, in order to fit”*. She framed this as being *“very good for me—to do a bit of reorganisation”*.

Everyone had rails and other assistive technologies in their houses (most commonly in the bathroom). At Raphael’s, the only modification seemed to be a seat over the bath. Similarly, Evelyn had added a stool to her bathroom, so she could sit at the basin to wash her hair.

Preparing the worker (training)

Between the instrumental and the intrinsic there are some broadly-bureaucratic tasks. Clients actively trained workers; they informed new support workers of the particular ways their home functioned, how they like their cup of tea, whether they wash or do not wash their hair on Mondays. Some taught the worker how to shower them, how to change a pad or assist with dressing—skills which the worker might use elsewhere. There is training, too, that clients undergo. This is especially true for people with certain sorts of impairment, who have been determined as being able to learn how to function in ways that more closely resemble some socially constructed ideal. Amongst this group are people with acquired or congenital brain differences or injuries.⁵⁸

Almost all clients gave examples of their role in training workers and the need to repeat it *“every time you get somebody new”*:

⁵⁸ The fairly constant training that people in the study with learning difficulties or brain injuries were ‘encouraged’ to do was a clear theme in the data. I have not reported it in detail here.

You have to train them. Well, train them in the sense that, yes, I like my mugs kept in a certain way, or um, the towels rolled up and not put in a flat pile. Simple things like that. But it makes a big difference to whether you can get at things or not. (Cornelia)

This also meant, as Cornelia argued, that rostering “needs to be consistent; [...] You need to know, if possible, that it’s going to be the same person”. Everyone agreed that fewer workers is better, because “they get to know you. They get to know the routine” (Laurence). “By the third time”, said Raphael, “you should just walk in and do what you want. You know what you need to do; just do it”. Workers who arrive and “get on with it” tended to, as Evelyn put it, “suit me very well indeed”.

The need to tell and retell, to repeatedly train new workers created irritation and discomfort for clients. Laurence said, “I just hate it when you’ve got to explain, um, time and time again, the routine. Time and time again”, and Norah echoed the sentiments of all other clients in the project when she said having to “keep telling them what to do [...] that’s time and if you’re tired and you’ve got a lot of pain, it’s that bloody effort [she was smiling and half laughing]”. The effort involved had led to several clients rejecting new workers altogether, even if it meant that no-one assisted them for that part of their schedule:

When they’ve rung up and said, “Oh, so and so’s away and someone else is coming”, “Look,” I’ve said, “It really doesn’t matter. I have a friend coming today; they’ll help me”. You know, I’ll make an excuse; I’d rather they not come. (Winifred)

It had similarly made Evelyn wary of consumer-directed care (CDC). She had met the case manager several times to work out her CDC budget. Perhaps the most telling remark she made was that the budgeting, checking, reminding, and managing made her tired. She worried that having to manage the workers and the package itself would require more effort than she could muster. As she put it: “I don’t know whether I want control now” (Fieldnotes).

Having a person come to assist drew attention to clients' limitations and undermined their presentation of self. Workers may not comprehend how much a client can do, forgetting, for example, that the laundry they left for Norah to put away would still be there tomorrow:

if you ask them, they'll hang it up for you [Norah laughs cynically]. Um, 'cause I find that hard to do [...] If, if you're capable, you can do quite a few things, [but] I can't stand there and put the clothes in the wardrobe, um ...

Raphael told me about Tanya who had efficiently done the shopping, and brought back some nuts he had been looking forward to eating. She then stored the nuts in a high cupboard; Raphael had to wait for assistance if he wanted a snack. The ordinary life that support could maintain was out of reach.

These actions disabled clients. Tasks they had formerly done for themselves now required laborious explanation to achieve. Clients had sometimes to decide whether to try to manage tasks alone, go without, or (repeatedly) remind workers about them.

Preparing for the worker: Emotional and intrinsic

The intrinsic or emotional tasks and actions were nebulous but influential. Clients could request or instruct, but they needed to do so in ways that both did not imply a negative judgement of the worker, and increased the likelihood of being treated gently. They needed to manage their own shame or embarrassment about being assisted to wash or use the toilet, and social norms decreed that they thank workers, whose very presence reminded them of limitations and who may lack initiative, kindness or competence.

Becoming a client

Becoming a client was a stark threat to people's front-stage presentations of competence. Media and literature discourses construct being cared for or supported as something to be feared and resisted. Raphael's attempts to

describe his role are congruent with the negativity of these discourses. He began with *"I'm the victim here"*, then said, *"Not the victim—I'm the patient"*, before concluding, *"I'm the client—call me what you like"*. I asked participants about this role. As well as sparking some of the training discussion, their responses drew attention to the emotional aspects of service receipt. Becoming a client and first-time encounters with workers were *"difficult"* (Winifred), and uncomfortable. Norah disliked the new experience of asking for help and Olivia talked about the challenges of depending or relying on others. She put this in terms of learning to accept dependence as a *"journey for the self"*. They were all describing the work of managing their own emotions.

Clients had to adjust to the emotional challenges of relinquishing control over some activities and places. Evelyn told me a story that showed that early in her receipt of support she had not learned the unspoken rules. After going shopping with workers she would—from habit—move to carry the groceries from the car boot into the house. Workers, she said, would often suggest that instead she put the kettle on:

I didn't realise at first what she was doing. So I came in and put the kettle on, made us a cup of tea and so on. And then she'd come with the shopping. And then, she said, "Now you go and sit down and have your cup of tea. I'll let mine cool while I put the things away". "No, I'll put them away, later". And of course, that's part of the whole object of, of the support worker: helping with the shopping and putting things away! And I'd, I didn't—that was foreign to me [laughs] [...] And I thought, "I could do this!"

She wondered whether her reaction to the workers' suggestion that rather than help unload the groceries she make a cup of tea was her *"wanting to stay in control, perhaps?"*.

Learning to be supported required learning a new script, and the role often begins at assessment. To receive government subsidised services, potential

clients are assessed. Bill joked about the official gradations of impairment he had moved through, but asking for help shifted how clients thought of themselves. Olivia was aware of the performance aspects of this process. She described ways in which some parts of the 'system' (a word she used ironically) encouraged people to "*perform worse than they are*". Olivia had made the mistake of 'talking' herself "*too high. [S laughs] And I only got three and a half hours*". She later realised that "*you're supposed to be downtrodden. You know, I, I can't comfortably do that. But that's, that's what you're supposed to do, and some people I guess are quite adept at it. It's how the system works*". In other words, an adequate performance of the sick role is required, and Olivia's was deficient. This is the flip-side of the phenomenon in which people with dementia perform a fully-competent version of themselves, convincing assessors that there is no need for any assistance (this is mentioned by Stacey, 2004, p. 61). Rather than perform to gain support, they performed to maintain their independent self.

Clients made emotional preparations before service encounters. Norah prepared herself "*Mentally. Yes. When she knocks on the door, I think, 'Who is it? What is it going to be like?'*". Winifred said that when she "*was getting different people. I, I was almost a nervous wreck!*". She continued, "*last year, I, you know, I was so unwell, and I wasn't used to being like that, and, er, yes. I'd be quite nerovy if there was somebody different coming. I'd be really quite upset*". I was present when an unfamiliar worker arrived (late) at a client's home:

Evelyn looked a bit discomfited. And [later] she said she "found it really ...", she felt "quite anxious about having a new worker". And it made her "quite jittery". It was quite clear that, yes, she was quite jittery about it. Um, and a little bit, um, like most people when they're anxious, she started to get a little bit snappy—ah, like she

wanted to make sure the rules were in place, or she wanted to make sure things were going to go the way she needed them to go. (Fieldnotes)

That clients were anxious or thrown by new workers is an indicator of the emotion work their familiar workers were doing and that was needed in the support work role.

When encounters went well, clients and workers could both present competent selves. Just as workers did emotion work to create the 'proper state of mind' in themselves and clients, so too did clients work to shape the encounters.

Winifred said that *"having the help now for such a long time, I know how to say hello and, you know, be nice to them [laughs]"*. Olivia said that she *"set my tone before they come"*. In interactions with workers other than Joanna, she said *"it's almost like I have to be really cheerful for these guys"*. Encounters with new workers or with workers she did not warm to were *"hard"*, but Sally told herself, *"you've got to make an effort"*. This task could be laborious; one worker had been *"here for two and a half hours and she wouldn't talk to me. Oh she said a few words, but there was no conversation generated from her. It was all me doing the generating"*.

Evelyn, too, spoke of the effort she made to shift both her attitude towards and treatment of a worker. Evelyn did not warm to Ann-Marie, who *"drove me mad after the second visit"*. But she reflected on her own manner and *"thought, 'Right, I speak very quickly. So I probably drive her mad'"*. She worked to find what Raphael had called *"common ground"* with Ann-Marie:

Anyway, I thought about it and I thought, "I'm not making an effort to find out more about you, so part of the blame is mine, I think". So then I, when we were sitting having cups of tea, [...] So we talked and I tried to find out what she was interested in. Throwing a few subjects at her.

Evelyn's efforts went on for eight months before she finally asked that Ann-Marie no longer be sent to her.

Finding common ground was beneficial. Winifred's approach was to "*just try and be as nice as I can [both laughing]. I try to put them at ease*". She put herself in the workers' place, thinking, "*well, they must feel strange, too*". Laurence's long experience of support work had taught him that:

if you give people, um, a fair go and you listen to people and you are a sounding board to their, um, to whatever they have on their minds, I have found having that quality that I can do, I find that the connections and the, the connections are stronger, rather than "Do this, do that, do this". I am more interested in the person and the way they think. And I, um, if you do that, um, and the person can open up to that, they can actually be stronger.

The work went better, "*because they're more laid back; they are more restful*".

Workers "*can talk to me about anything, really [...] It's that bouncing off each other*" (Laurence).

Clients' emotion work here was focused, perhaps with enlightened self-interest, on establishing satisfactory relationships which would, in turn, alter their own experience of the encounter. For some, part of this work was directed towards making sure their own impact on workers was benign, often extending to real concern for workers' wellbeing.

The gratitude game

Gratitude was a form of emotion work that some clients performed to alter the way support was delivered. Winifred, for example, said "*It's wonderful.*

Wonderful. I can't speak highly enough of them". And Sally was "*grateful they come!*". She was "*usually quite pleased to see them, and even when there's somebody different*", though she qualified this by saying, "*I am naughty—I keep counting the days. I think, "Oh, thank god, it's Anita again tomorrow". You know, I'm so pleased*". Mostly clients were overtly and frequently grateful. During observations, they

used ‘please’ and ‘thank you’ very often,⁵⁹ they smiled at workers and reported the exchange of small gifts and treats. Evelyn took an interest in one worker’s grandchild, sending her *“little things that I find in shops”*.

But gratitude has no place when experiences are not positive. Then, the most common response was ‘putting up with it’, or declining a particular service from that worker. This was particularly relevant to personal care. Norah described being showered by people who were *“rough, when they wash you — that’s not necessary”*. Her not wanting *“to complain too much”* acknowledged the role of gratitude in maintaining relationships. It was apparent that many clients worked hard at this, even when they found it very difficult. Olivia recounted being driven to an appointment by a worker who *“didn’t know where to park, and I had to walk”*. This made her *“really, really, really, really grumpy”*. She tried *“to get myself out of it. But I couldn’t. And so we had a really awful time”*. Bill, who was grateful for the workers who did a good job, did not try to keep his temper with those who he believed were dishonest; he reported saying to one worker, *“Well, I’ve got a simple explanation for this [incident] You’re a liar!”*. He regarded being lied to, and workers staying for less than their rostered time, as an insult: *“You’d feel he thought of you as an idiot—for a start off”*. *“They talk bullshit, because they think I’m old and stupid, and I don’t know how you feel when people take you for a fool, but ...”*. Bill’s angry rejection of dishonesty or poor performance also protected the self he wanted to present.

Olivia, Bill and—more quietly—Laurence, Raphael, Norah and Evelyn gave examples of their resistance to the ministrations of the occasional unkind, lazy, dishonest or incompetent worker. These clients also resisted what they regarded as obfuscation or platitudes delivered by some of the more senior staff to whom they complained. Norah, Olivia, Bill and Laurence all made direct approaches to rostering or other more senior staff (administrators and nurses),

⁵⁹ Raphael’s use of these grace notes sometimes sounded sarcastic and like part of a routine.

identifying—with varying degrees of politeness—the problems they saw and expecting change. Evelyn and Raphael had also done so, but very mildly. Norah was critical of senior staff who waved away residents' complaints, and Bill reported several similarly contrary experiences with his service provider organisation.

There were costs in resistance and in failing to be overtly grateful. Olivia believed her failure to perform the sick role, to be mild, overtly grateful and to not complain had earned her a poor reputation with Hillcrest, and Bill's wife certainly thought his reactions were counter-productive. Olivia said that:

If you're not [performing victim or unwell], they come two ways: like you should be more, but they also then doubt that you—like somebody at Hillcrest—the person that I just dislike the most, the roster clerk, said to somebody, "She's not really blind". Because they saw me at a tea and because I'm really competent and I handle it. "She's not really blind; she doesn't deserve all this".

Olivia did not label herself as sick or impaired, or indulge in mendicant-like gratitude. Instead, she reserved overt expressions of gratitude for the more unexpected or beyond-the-call-of-duty instances of support. And then the praise was precise and warm. This was also true of Bill's responses to Brian, and Sally's attitude to Anita.

Emotion work and the body

For most clients in the study, the body was transformed from being a taken-for-granted part of their everyday performance, to being subject to their own and others' surveillance. Its acts made for untidinesses that, rather than remaining hidden, were now exposed to support workers. As some workers' reports in Chapter 5 showed, there was potential in body work for encounters to stigmatise clients and damage their presentation of self.

Risks to presentation of self were much greater in personal care. Here, the body itself is acted upon—to be dressed, or shaved or cleaned, to be propped, or wheeled, or laid down or turned. Its functions are the focus of attention. Vic spoke of the attention given to residents' bowel habits. No excretion passed unnoticed. When James went without a bowel movement for two days, Vic described the panic amongst other staff which ensued. This in turn created *"pressure on James"*. Part of James's work became the work of producing a bowel movement, and his overall wellbeing appeared secondary to whether or not he completed that task.

I asked those who had assistance with personal care what made for a good or bad experience. The responses contained similar elements: workers needed to be efficient, prepared, gentle, alert and supporting. Clients needed to explain to workers how best to assist them, and attempted to create 'the proper state of mind' (Hochschild, 2003b, p. 7) in themselves and the other that would minimise embarrassment for both. The ritual and potential joy of washing could easily become something to be endured. Though she understood that workers *"want to be so quick and efficient"*, Norah needed *"somebody who can gently help you to clean yourself"*. Instead, some workers would *"grab hold of you and rush round you"*. In Chapter 5, we heard from Shirley and Anita about the risks of rushing; Norah had asked some workers to *"Slow down; you're hurting me! [anxious tone]"*. She—and several others—sometimes found herself saying, *"I'm not going to, I'm not going to have a shower if I've got to have a shower like this. I need somebody kind and helpful"*.

Being naked did not bother everyone. Raphael was *"more concerned about my balance, concerned about falling"* in the bathroom. Sally, though, *"could no more walk around naked, than fly on the moon"*. She had learned to suppress her deep discomfort, *"because I know I've got to"*. She and others created the proper state of mind by deploying strategies to minimise exposure of their naked body.

Sally drove her chair *“sort of to the edge. Um, I stand up—I’ve got a bra, I hang on to that”*. Workers washed *“all the bottom half. Then I sit down and they do the top”*. Winifred used flannels to cover her crotch and chest, and employed a sort of sleight of hand during drying so that these parts were never seen by the worker. The worker dried her back and legs, but Winifred *“managed”* the rest. Most female clients said they did not like *“the fellas doing”* (Sally) personal care. The much greater numbers of female support workers meant that the men had less choice.

Nakedness was also discomfoting for some workers, and clients were alert to workers’ responses to dealing with the naked body or body parts. These encounters were *“potentially embarrassing or awkward”* (Laurence), and workers’ reactions affected client identity and comfort. Raphael liked workers who *“feel at home here, and who don’t treat me like they think there’s something wrong with me”*. As Laurence put it, *“If a worker doesn’t worry about that—you don’t worry about that. And, really, really—I’m part of the whole thing, you know what I mean? It’s nothing here or there for me. Yeah—for me—after a while you get, you get used to it”*. Raphael gave examples of workers who created ease. These were people who *“do it with no hesitation; no limitation; nothing is too difficult”*. I asked whether this meant they thought, *“‘This is normal?’”*. He replied, *“They don’t know what abnormal is [...] [They have n]o boundary at all on normality. That’s the way that I see the workers that come in here. There is no such thing as “Yeuch”. No such thing as “Yeuch” [Raphael laughs]”*. This echoed Lilla’s *“nothing was a drama for her”* description of her grandmother. Raphael’s own relaxed attitude to nudity enabled workers like Brendan to produce a gentle and thoughtful performance: *“Brendan [...], ah, he describes each movement: ‘Now we’re going to do under your arms; now we’re going to do your back; now we’ll do your legs; between your toes ...’”*. There were workers who *“get a bit, um, thingey about it”* (Laurence), and did a *“poor job”* (Raphael). *“A poor job is she only works on my back!”*. It seems likely

that the eye-contact-only and back-washing strategies employed by Stella, among others, reflected their own shyness or anxiety as much as their sensitivity to the client. I asked Raphael what he did when workers only washed his back: *"I take the soap out of their hand and do the rest of me. She stands there with the hose and hoses me off"*. 'Hosed off' is a particularly striking description, a reminder of the lack of care and attention some clients experienced.

Workers who were not at ease effectively disabled clients. Sally—like many others—did not have a shower every day (though a worker came for that purpose), since *"it's psychological"* and *"depends on the girl [...] I'll have one tomorrow, as long as the right girl turns up"*. Being bathed by unfamiliar, careless, unkind or inattentive workers created anxiety. Being naked in the presence of a stranger, clients revealed not only their bodies, but also the signs of conditions. New encounters could be constant reminders of fragility and of being reliant. Clients worked to manage their own feelings of shame, exposure and their responses to these reminders of frailty or impairment.

Summary

Clients were working before and during service encounters. They learned a new identity, and *"reflected on their everydayness"*,⁶⁰ bringing to mind the minutiae of their hitherto unconscious habits. And they accepted, prepared, managed, thanked, resisted and rejected to create the 'proper state of mind' in themselves and in workers that would enable the presentation of their chosen self.

Several clients demonstrated agency to shape or control interactions. Rather than have their expectations or assumptions about themselves undermined by their client role and supports, they used careful gratitude, complaining, or

⁶⁰ Pers. Comm., Brendan Churchill, May, 2015.

humour. These labours reinforced or protected the competent self. Raphael did not “*get much patronising*”, because he “*controlled it*”: “*I can make you laugh—if I can make you laugh, I’ve got you right here*”.

In interactions, clients also worked to minimise shame. They (and workers) used civil inattention (Goffman, 1963a), balancing being alert to the other with signalling that they were not “a target of special curiosity” (p. 84). This signal of safety—that the other has “nothing to fear or avoid in being seen and being seen seeing, and that he is not ashamed of himself or of the place or company in which he finds himself” (p. 84)—was needed by both worker and client.

Some of the work clients were doing took a toll; Evelyn and others spoke of tiredness and the exacerbation of physical ailments. Emotion work could be, as Olivia said, “*really hard*”. The small body of research about clients doing emotion work has described how disabled people worked on their emotions in response to having few choices; a kind of learning to put up with it. People managed the feeling rules of situations by learning to “show emotions that were ‘appropriate’ for those receiving care (see Morris 1989)” (Liddiard, 2014, p. 9). Here, some people worked to put up with it, some worked to create successful interactions, but several went without instead.

Theme 3. How clients talk about workers

The ‘verbal statements’ (Goffman, 1967) clients made about workers depicted them as competent and capable, ‘good’ people, attentive—or the reverse. Talking about workers was another opportunity for clients to reject their ‘needy’ or failing status.

The first remarks about workers were usually appreciative, and focused on their dyad partner. Then other attitudes were revealed as they made comparisons between the dyad partner and other workers. For every virtue described, the clients also talked about their opposites. Thus, they spoke about

workers who were inefficient, lacked initiative, seemed unable to do the requisite work, or were inattentive and oblivious. They described workers who behaved robotically, or who lacked empathy, and workers who were dishonest or angry. And they made it clear that they cared about many of the workers, expressing concern for the difficulties they experienced. In all this, clients revealed subtle distinctions of taste, opinion and need or desire, as well as social class,⁶¹ and were continuing their presentation of self.

The unaccepted worker: Reasons to say no

She'd come in, hat, gloves, scarf and it was mainly winter time [...]; when I knew she was coming I'd move all the stuff that could be damaged. And she'd go, undress, undress [mimes casting off outer clothes more or less randomly], and sit. [...] I never had any games set up when she was here. She'd dump everything, then sit and "How are you today" [patronising tone], um, sounds a bit bitchy. And we'd talk for a while, "Would you like a cup of tea?" [E asking worker]. "Yes, that'd be nice [same patronising tone]". So I'd get [make] a cup of tea. (Evelyn)

Clients rejected some workers—and it was almost always because of practices or habits that were undermining or disabling. Evelyn was the first person to mention Ann-Marie, whom she began by describing as *"a bit ethereal"*. *"She's away with the fairies; she's got this lovely manner"*, said Evelyn, searching for positive ways to portray Ann-Marie. Then, giving up, *"No,"* she said, correcting herself, *"this strange manner", which annoys me sometimes"*.

Then, I heard about a *"vague"* worker from Olivia, about an inefficient worker from Raphael and about a worker who was just *"off"* from Sally. In each case, it

⁶¹ Social class, here, references Bourdieu's conception in which consumption and lifestyle are indicators of class. Rather than referring chiefly to access to and control over wealth (economic capital), class distinctions are evident in social, cultural and symbolic capitals (Giddens, 2006, pp. 322-323). That is, social class refers to both position in the relations of production, and to the impact of social, cultural and symbolic resources, like reputation and patterns of consumption and aesthetic commitments (Weininger, 2005, p. 94).

was Ann-Marie. At first, they protected her, saying *“I shouldn’t say the name!”* (Olivia). Raphael spoke about a worker *“that he hated because she was actually ineffectual and never finished anything. He also said something about not wanting her to provide any first aid”* (Fieldnotes). When I said that some other people had used the phrase *“Off with the fairies”* to describe a particular worker, he replied, *“That’s her”*, and then used her name. Ann-Marie was the first worker Olivia met; *“after she’d come for two weeks, I thought if this is the service, I don’t want it”*. Ann-Marie was *“always somewhere else”*, she was *“vague, and then she’d go off on a tangent, and just sit down”*. As well, she was *“not present to me or the situation”* (Olivia).

Clients did not see Ann-Marie as unkind or rough, but she embodied several characteristics that they disliked and was seen, ultimately, as incompetent. She was inefficient, lacked initiative, was inattentive and absorbed in her own internal world and oblivious to the nature of the people she was visiting. These traits—and their opposites—were described when client participants spoke about workers.

Incompetent and inefficient

Most clients presented themselves as systematic and very much disliked workers who were incompetent or inefficient. Laurence described one person as *“so incompetent [...] I would tell her different steps of doing things; she would do the complete opposite”*. Her lifting technique, for example, was *“Bad on her back, bad for me”*. Sally seemed infuriated by a worker who was *“just bloody hopeless”*, and said *“none of them”* made the bed properly. Winifred was rarely critical, but she disliked workers who *“you know, cleaning the kitchen or the bathroom—especially the kitchen—[...] they don’t know whether I’ve been having fish or chicken on my cutting board, and it just doesn’t get washed”*.

Competence was appreciated. Olivia delighted in Joanna's competence and thought that *"Joanna would get a sense of her own competence. You know, feel the joy of doing things well"*. The work was:

satisfying [Joanna's] need to be in the world with this ability to contribute to others. There's a satisfaction in that, I think. Even for those that feel downtrodden and there's no pride in it at all, there's still a satisfaction, um, yeah, [...] So there's a need to be recognised as having some meaning, some importance, some skill that they can contribute.

Clients wanted workers to be present, and regarded *inattention* as a key form of incompetence. *"You have to be present when you are working with disabled people"* (Raphael). People might come to work unhappy, angry or otherwise inwardly focused, and bring emotions to work that affected clients. Laurence described this as having *"a lot of baggage coming to my front door"*. These workers were, as Olivia described it, *"kind of concerned with their own concerns"*. While clients could *"understand that, sometimes"* (Olivia), they resented the repetition of such absence.

Inattentive workers did not remember what to do from their last visit, and did not pay attention to the way the client liked (or needed) things to be. They were perceived, as Sally put it, to lack any *"interest in me"*. Sally wanted workers to ask how she was, ask *"how long have you been sick, or I don't know ..."*. Olivia felt Blanche had several other things on her mind and was *"not in a space where she's really caring, authentically caring about me"*. These sorts of inattention and inefficiency could be disabling for clients.

Efficient or officious?

Conversely, being too efficient could also be disabling: efficiency could shift into officiousness. Clients also spoke of patronising behaviour; the most common form was workers stepping in to do things of which clients were capable. There were also 'bustly' workers who were in a 'hurry'. Norah gave

the example of a “girl” who “comes in bright and chatty” when Norah was “still nearly asleep”. Norah “had so much pain in my knee and in my leg”, but the “girl” seemed oblivious, asking:

“How are you?” And I said, “Ah, oh, I suppose I’m alright”. “Come on, you’ve got to get out—it’s shower time”. I said, “Yes, alright, alright” [sounding bustling]. Push you along a bit. It’s a lack of understanding about how we feel, I think.

This treatment exacerbated clients’ impairments or limitations. Laurence saw such workers as “quite selfish”. Some would “go into a work space and treat it as a work space”: “‘I will do what I want to do—only so much and then go to the next work space’. Very, um, automatic. Robotic”. There are other explanations. Perhaps workers were alarmed by the evidence of frailty, tiredness or difficulty that confronted them (and see Bedell et al., 2004; Isaksen, 2002), and adopted bustling cheerfulness as a shield. Perhaps they were worried about managing time constraints, or intimidated by clients.

Culture, race, class and support workers

Clients could be intimidating. Bodies could present a challenge to the expected order of things, and mismatches in culture, life chances and social class could signal differences in social status. Olivia wondered whether one worker’s remark—“We’ve both got disabilities and, you know, you’re blind and I’m deaf”—was an attempt to find common ground. She resisted, telling the worker, “that’s not how I describe myself”. Laurence thought that power imbalances drove some workers to make everything “fun and games [...] a joke”. They “like to kid around with you because [they] know that you are intelligent, but [they] would like to bring you down to [their] level—[to] feel in control of you”. This fitted with the bickering between Blanche and the client, Olivia, and with remarks made by the workers Tilda, Tash and Blanche (reported in Chapter 5) that positioned clients as having greater (and undeserved) privilege than workers.

Almost every client wanted workers with whom they could have an engaging conversation. Nicko could not remember the name of one worker — *“that’s how important he was!”* — who had simply sat with him, as if babysitting a sleeping child. Olivia was annoyed by the *“magazine minds”* of some workers who wanted to discuss ‘the Kardashians’, a topic that she and Evelyn both found uninteresting. Evelyn was more irritated by a worker who talked at length about her child; Raphael, Cornelia and Olivia made the same complaint about different workers. Olivia *“really want[ed] to see the value”* in a worker who *“talked about being a mother”*, describing her efforts to appreciate this worker (which mirrored those of Evelyn with Ann-Marie) as *“my work for those two weeks”*. But it was *“really, not what I want every week”*.

Differences between clients and workers related to issues such as class, cultural capital, gender and race seemed to lie beneath comments such as *“magazine minds”* and clients’ use of the word ‘girl’ for women workers. Norah alluded to social distance when she said, *“you can’t complain about the carers, ‘cause some of them are so uneducated. You know, they talk about ‘youse’ [...] their grammar is shocking. She had “learn[ed] to shut [her] eyes to that”*; the worker she most liked at Cliveden was *“like that”*. Cornelia spoke of Tammy as *“pretty much uneducated”*, and therefore *“more or less stuck with this, kind of doing other people’s housework for them”*, a sentiment echoed by Norah and Raphael. Clients were, by and large, quite sure that care or support work was not something they could have done, again reinforcing social or class distinctions (and see Fine’s work on the social division of care, 2007b). They thought that this work suited some people, because of limited employment options, or natural aptitude. Sally described one worker as being *“probably born to be a carer”*, and Laurence thought Gina was *“a natural at it, in every which way”*. These remarks echo what the vocation-driven workers had said. Clients’ use of the term *“girls”* to refer to workers who were in their fifties, or older, and often from culturally and

linguistically diverse backgrounds, further reinforced divisions. They were also evident in Evelyn's irritation at Ann-Marie's drawl, and in other clients' recognition that they and some workers had very little to talk about.

Lack of shared interests or intellect was demonstrably a far from fatal flaw. Clients' 'bug-bears' were relaxed for workers with whom they had a bond, and "*attitude and endeavour*" counted. Stella was, as Raphael saw it, "*not the sharpest tool*", but, "*her attitude and her endeavour—very high. Very high. Her work ethic*", and she was "*kind and nice*".

Lacking initiative

Most clients, unbidden, told me they disliked so-called 'agency' workers (also a strong finding in Woodin, 2006).⁶² These "*plug-in*" workers were usually unfamiliar, and seemed to lack initiative:

Running the washing machine, Brendan comes in, looks in the washing machine, says, "is no one even doing ... when was the last time someone did the laundry?" He doesn't wait for an answer. Turns on the washing machine, puts it on the airer when it's finished. Other people wait till it's full, and then ask me if they can do laundry. Don't ask me for Christ's sake if you can do the laundry—just do it! See what needs to be done—do it! You don't need permission. (Raphael)

Perhaps their lack of initiative was because, as Norah suggested, "*they don't feel confident about doing anything*".

Lack of initiative may also have been a strategy. Perhaps workers were compensating for their poor pay and highly prescribed work by being stubbornly pedantic, rough or careless. Or were they trying to claim agency by exerting their power to do less? Bill thought that underpaying people created workers who say, "*Why should I work a full hour, and be paid peanuts? So if I can*

⁶² Community and residential provider organisations sometimes broker services from other providers—to fill gaps left by sick leave, for example.

diddle the bosses, I'll do so'—and they do it". Olivia grouped 'doing gender' (West & Zimmerman, 1987, 2009) in the same strategy:

Like there's, there's a game Blanche plays, which is a game women of my mother's generation used to play, and it's called 'Aren't I stupid!'. And they, they just like—you know, she puts things in different places, she doesn't hear what I'm saying. But I know it's not her intelligence that's lacking. So once I realised it was the game, I just tolerate—I just move all the things back when she's gone and things like that.

Playing stupid involved “a lot of activity and movement”, but resulted in poor performance of the day's tasks.⁶³

From lacking initiative to dishonest

Workers' efforts to exercise agency appeared again in clients' remarks about dishonesty. Raphael was frustrated by workers who asked what to do and then did it poorly. For example, “*they vacuum in a circle*”. I asked, “*You mean this circle here?*”, indicating the centre of the lounge room floor. “*Exactly!*”. “*What do I look like, I'm stupid?*”. Raphael (along with Laurence, Winifred, Bill and Olivia) had rejected workers for the “*things that they don't do! Like, you have to kick them in the arse to get them starting*”. Winifred, in a more circumspect fashion, noted that some workers “*don't like having to do, they don't like the housework. I think that sums it up*”. Bill told me that, “*of the half a dozen people that would come, three are good [...] They say an hour and they're here for an hour. The other three vary, as I say, between fifteen and thirty minutes*”. He had described Brian to me as “*reliable*” and “*honest*”, qualities he regarded as essential. Now he linked what might be passed off as laziness with dishonesty. He argued that not completing tasks adequately and working for less than the rostered time were forms of theft; these workers were in effect stealing from clients and employers. For Bill, Raphael, and Laurence such dishonesty *implied* their own incapacity. The

⁶³ McLuhan, Pawluch, Shaffir and Hass's (2014) 'cloak of incompetence' may be applicable here.

subtext, as Bill saw it, was that he was incapable of recognising the deception — the “*stupid*” to which Raphael referred.

Leaving early or arriving late and not making up time, leaving jobs incomplete, or being deceitful or patronising were obvious ways in which some workers were unethical. But there were other sorts of unethical behaviour described. For example, some workers had a “*lack of boundaries*” (Olivia): they talked about other workers or clients. Evelyn was disturbed when a worker asked her what she thought of Ann-Marie. Sally said that workers confided in her — often about things to do with other workers or clients. Workers had told her “*things that they shouldn’t*”. Instances of being confided in raised the possibility that these workers might also be indiscreet elsewhere. Despite this, clients’ favourite workers were ‘allowed’ to break this and other rules. When Joanna made critical remarks about work, Olivia was sympathetic, and “*let her vent*”.

Clients caring about workers

Olivia’s permissiveness with Joanna was a common phenomenon in the dyads. Clients expressed concern about the vicissitudes of work, workers’ spasmodic bouts of tiredness or grief, and the personal difficulties workers faced. Bill talked about a tragedy in Brian’s early life, and a traumatic accident. He saw them as having reduced Brian’s opportunities but enhanced his capacity as a care worker. Olivia mentioned that there were “*some things*” Joanna had “*been through personally*” that had similarly given rise to “*more self-understanding*”.

Sally displayed fellow-feeling for Anita, telling me about family members for whom Anita had an informal caregiver role, about a major accident which had almost killed her and about Anita’s stoicism during cancer treatment:

And d’you know, she used to come to work in between treatments. Like she’d have chemo, say today, this week, and then not for another three weeks. Course she would

*be really, nearly dead for the first week. She had mouth ulcers and—oh. It would have been just—you couldn't imagine what she went through.*⁶⁴

Norah expressed empathy with Courtney who *“had a husband that knocked her around and I doubt whether she had much of a childhood”*, and Evelyn was worried about the problems Blanche was experiencing at home.

Workers, said Olivia, *“don't speak up for themselves”*. She, Bill, Sally, Norah and Evelyn were concerned that workers simply accepted rostering decisions which placed them under pressure. It meant they sometimes came to work unwell (as Anita had), and tired. Sally said that *“Anita sat down the other day—I said, ‘For god's sake, sit down. I'll get you a cup’. She just wasn't well!”*. As well as being concerned about Anita's health, Sally was also worried because the deaths of several clients had left Anita sad and fragile.

The embraced worker

There were plenty of workers that clients described in positive terms. When speaking about the workers they held in the highest regard, clients' tone changed. They smiled or sometimes laughed. They talked about the happiness they experienced. When Raphael talked about Brendan, there was an amused and energetic tone—he often sniggered, or laughed out loud. Brendan exemplified what Raphael liked: *“people who feel at home here. And who don't treat me like they think there's something wrong with me”*. *“You get the feeling I like him?”*. Brendan was simply *“a good strong man”*. To Nicko, Leonie was *“a smart lady; she knows what my forte is. She's pretty clued on to me too—she can tell when I'm lying [both laugh]”*. He said that she and the other members of the support group *“like to see progress in a person. To see—I mean it would be like you doing a job for someone and getting a good feeling about it”*. Brian, said Bill, was *“extraordinarily good, one*

⁶⁴ That Anita chose to come to work, despite the rigours of treatment may reflect her work ethic, or the fact that her low wages were essential.

out of the box!". As well as being honest, *"in here [Bill taps chest], Brian's a superb nurse"*. Sally looked at her roster and said, *"Oh, thank god, it's Anita again tomorrow [...] My life becomes ship shape again"*. Anita was funny, *"I mean if she's telling me [stories] in the shower, well that's diabolical. Mainly 'cause I can't move cause of the laughter. We've had some good laughs. So she's good for me"*. Winifred and Sally both simply relaxed—as if the weight they were shouldering had been lifted—when they recounted time with Shirley or Anita, respectively. Olivia almost visibly expanded when she talked about Joanna and they seemed more energetic together than apart. attentive, or *"totally present"* (Olivia). Such workers made the effort, as Nicko said, to *"learn what I was like"*. They tried to ensure real needs were met. Sally told me that when Anita had hurt her back or was unwell, she *"rang her friend to come and do the work. They really look after their clients"*, a form of caring that Winifred also reported. These workers paid *"attention to every little detail"* (Laurence), so that, as Sally said, *"you don't have to tell her to do anything [...] No, she's got too much common sense"*.

Being present was supplemented by being *"thoughtful"*; Edwina, for example, was *"caring and she is interested in you. Or anyone!"*. Brian *"cared what happened to the people. He treated them like people instead of like a number. He didn't talk down to them"*. Thus, attitude was a key dimension of workers' performance, and more important than intelligence or education. Raphael summed this up when he joked about titles for a section of this thesis, saying *"Smart's not part of it. Smart's not part of it. Sounds like a book: Smart's not part of it. 'I was a darned good worker, and smart's not part of it' [...]. Attitude's got a lot to do with it"*.

The role of provider organisations

The data showed that despite clients valuing many workers highly, organisations did not necessarily agree. Clients made a lot of remarks about their own and workers' treatment by organisations (as had workers—see Chapter 5). Organisations were seen as sometimes incompetent, inattentive or

unresponsive, and some pushed workers around in various ways. There were also ways in which organisations positioned workers and clients as incompetent, somewhat child-like others.

Clients' views about how organisations treat workers

Clients were concerned about how organisations treated workers. Winifred remarked that the Many Hands *"roster manager cooperates very well with all of the girls"*, but felt that management did not always prepare staff well for visits to unfamiliar clients. When *"different girls come in, they've never been here before, they don't know what they have to do. Management hasn't told them"*, echoing the very strong theme across the data of the problem of unprepared new workers.

Workers being treated casually by organisations was commented on by several clients. Norah, for example, said that workers at Cliveden *"don't get much choice anymore"*. They *"can't always get the hours that they want. Or the shifts they want"*. Several had decided to leave. Laurence, too, thought that *"support workers get burned out"*. His previous providers had *"overwork[ed] their workers, um, for not a lot of pay"*,⁶⁵ and did not *"value their support workers in terms of a range of different, um, issues, in terms of the pay, conditions, attitudes"*. Some clients also worried that the increasing adoption of smart-phone and tablet technology for rostering and management would *"mak[e] more work for [workers]"* (Winifred). As they moved between different tasks, workers now had to *"click off and put it in their phone. And, you know, [...] They could be showering me when something else happens!"*. They worried that the technology was potentially intrusive and would impose a new set of controls on workers.

⁶⁵ Australian workers' pay rates are mostly determined by the centralised wage fixing system, but individual organisations may negotiate for fairly minor variations to the 'award'. These may affect hourly pay rates, but usually only slightly; most provider organisations remunerate workers within a fairly narrow range. Conditions are more variable, as the example of daily travel claim limits, described in Chapter 5, shows.

Rostering methods and decisions could, as Olivia commented, leave workers feeling *“totally unappreciated”*. For instance, Eva was rostered to visit Olivia first thing in the morning (after a very long drive); Olivia and Joanna described this as evidence that the organisation was not taking care of Eva. Raphael commented on the pressure poor rostering placed on workers, saying a worker had told him *“they had ten minutes to get from one client to the next”*, though the distances were *“impossible to do in thirty minutes”*. Clients also talked about the ways in which organisations failed to respond to the concerns of support workers. Sally felt that *“out here, [workers are] very much on [their] own, and sometimes they don’t get a lot of satisfaction going to their case manager either”*. Several workers had talked about requesting additional support for some clients, and clients commented on the impact of those needs remaining unmet. Sally knew that Anita was *“distraught about a certain person who she felt was really depressed and needed [...] but there was no support given from the case manager”*.

Another way in which clients thought organisations were failing workers was in managing unsatisfactory performances. Sally, Olivia and Evelyn all questioned why Ann-Marie, about whom they (and other) clients had complained, had not been either re-trained or asked to leave. No-one had been hired replace her, and clients who had rejected her then went without a service. Bill explained this, noting that workers who were out of favour, rather than being encouraged to improve their performance—or, indeed, being interviewed to see whether there were ways in which the organisation might change its practices—were *“just not allocated any time slots”*. Bill had also discovered that several workers did not have current first aid certificates—a story supported by things workers had told me, unbidden. Both these examples were evidence to Bill of *“that dishonesty again”*. Bill thought that in failing to appropriately manage workers who performed poorly or were dishonest, other workers—who *“care for people”* were *“being betrayed. I mean that seriously. The, something’s*

happened and the whole caring fraternity has been subverted or, or whatever word you want to use". Organisations' apparent collusion in workers doing extra, unpaid work, was also subversive. While it was "really good that the person is going beyond the call of duty", it was "not fair. And the company's certainly not going to pay her for that" (Raphael). Presenting his ethical and professional self, Bill argued that organisations are "run like a fifteenth century workhouse", getting rid of "old hands", so they can "feed" the newcomers "a lot of bullshit because they want a job and want it badly".

How organisations treat clients

Organisations marginalised or disabled some clients by failing to respond to their needs. Raphael, Norah, Sally, Bill, Olivia, and Evelyn gave examples of being short-changed by the various pressures on workers. Blanche was often late arriving on one of her rostered days, for example, because she was reluctant to rush the previous client, who was living with severe dementia. The client had sometimes gone missing, and Blanche had searched for her,⁶⁶ leaving Evelyn without a service. Raphael and Bill both talked about workers truncating their visits.

Organisations could affect clients more directly. Many clients reported that office staff regularly failed to communicate. Bill said that on only one occasion (in almost 20 years) had anyone rung him to check whether a proposed roster change was suitable. Both Evelyn and Raphael had experienced workers arriving with students on buddy shifts; neither client had been asked whether such visits would suit them. Evelyn was *"not cross, but I was taken aback. I could have been sitting there naked"*. On another occasion, the provider had — without checking with Evelyn — completely revised her roster based on a worker's

⁶⁶ It is unlikely that this was an efficient use of Blanche's time, though it does imply a form of caring. It is apparent that Blanche felt unwilling to call the provider to take on this role.

misunderstanding, and then been reluctant to reverse their error despite her protestations. Communication was, as Sally remarked “*sort of jilt, jilz, zilch*”, probably because “*the rostering person’s got too much work to do*”. This burden resulted in the sort of problem that every community client had experienced — unfamiliar workers arriving unannounced (and then sometimes being rejected), and compliant clients having visit times changed in ways that hampered their well-being.

Clients also felt organisations were failing to adequately respond to requests and complaints. In these failures, clients’ needs and rights were sometimes ignored; they were treated as child-like others. When Bill was critical of a worker, she had asked not to be sent to him again (telling the office that “*Mr [surname] says I’m useless*”) and the organisation had sent no one for several days. When Olivia asked that a worker not be sent because of her indiscretion about an elderly couple, the rostering manager replied, “*Oh—I wouldn’t have expected it of that one*”. This is reminiscent of Norah’s reports of a contrarian RN who batted away, but with a patronising smile, the complaints Norah made. Requests for better service were disheartening; they took “*too much of my energy*” (Olivia). She and Bill both felt that the outcome of such requests had been “*a punishment for my criticisms*” (Olivia). Bill felt that regardless of “*what went wrong—it’s the patient’s fault. Stupid old bugger. Doesn’t know what he’s up to*”.

Some clients pointed to systemic causes of the more serious failures. Each individual agency, according to Laurence:

can develop nice policies that look good, look great, and they go in big folders up on the shelf, and it’s good for the spiders [laughing], good for the spiders and cobwebs and no-one, no one can then get the cobwebs off until something legally, something

legally, like sexual abuse happens, and then they say, “Yeah, we’ve got them, but we don’t know how to implement them” —and it’s far too late.

Cornelia and Olivia, too, felt that the problems had system-wide causes. Olivia used her own experiences of work to understand how the system shaped the attitudes and actions of workers. As a student, she had seen *“how the system was sort of all-engulfing. It eats people’s intentions, and, and goodness”*. People *“move into there and find a comfort zone, with their own incompetence”* was how she described this phenomenon in community care and support. She and Bill were perhaps the most critical, but their critique was supported by what workers and other clients had said.

This systemic dis-ease was evident in two strikingly similar accounts of demeaning interactions with case managers and administrators (from different organisations). They point to a more extensive societal failure, also evident in public discourses (Chapter 4): clients as marginalised and undeserving others. Laurence and Olivia had conversations with office staff that implied that the services that were intended to support them to lead ordinary lives were a luxury rather than a right. Olivia had asked about including a particular item in her CDC budget. The response was *“‘That’s something you have to save up for’”*. This, Olivia said, was *“like talking to a, a child: ‘This is your pocket money and I’ll put it away every week and you can go buy those lollies for your knees!’”*. Laurence had been told by a roster manager that his organisation would not guarantee *“a flexible choice in terms of hours”*: *“you’ll have to settle, or people will have to settle for second best. It’s not like a candy shop”*. But, as Laurence passionately said:

Our ISP hours are not like candy or chocolate—you know what I mean? We don’t go to the shop and say, “Oh, I want ...” The ISP are essential for our daily lives! To

function within the wider community. And a lot of people and organisations in the services industry do not understand that.

Ignoring or throwing back complaints, failing to replace workers who left or who were unsuitable, treating supports that put an ordinary life within reach as luxuries, failing to communicate with clients, sending—unannounced—unfamiliar and unprepared workers, and making rostering changes that meant a service was provided some hours later than needed left clients disheartened. Sometimes the focus of their disappointment was an individual: *“the manager at Hillcrest does not really—[...] she just, I don’t think she really could give a stuff”* (Olivia).⁶⁷ For others, like Norah and Laurence, whole organisations had lost their way. It was *“all business now. Making money. I don’t think they really care [...] It’s not as personal. Um, they think they’re being cleverly careful or caring, but they’re not really”* (Norah). Bill’s perspective took in the whole system.

“[P]hilosophically, I reckon the whole thing stinks. And it’s in nobody’s interests to do anything about it”. He concluded that, to provider organisations, *“I don’t count”*.

Organisations set the tone, shaped interactions, were supportive, ‘caring’, or dismissive. They thus influenced whether clients could resist demeaning constructions and present competent selves.

Summary

Although this section has been about clients ‘verbal statements’ about workers, it also revealed a great deal about the clients themselves. In their remarks about the workers, they were showing their own needs, what they regarded as their own strengths, and their likes and dislikes. Their staunch criticisms of provider organisations bore out what some workers had said (Chapter 5), and displayed

⁶⁷ Other Hillcrest clients made similar remarks. But criticism was not restricted to one case manager or one organisation.

concern both about their own interactions and about how they saw workers being treated.

When clients were critical of workers' lack of intellect, their incompetence, or their dishonesty they were, by implication, also presenting themselves as being none of those things. But this means of presentation may have had little ultimate benefit. After all, the support they needed required engagement and that the worker understood needs beyond the instrumental. Resistance or complaints did not increase the likelihood of experiencing the "*common ground*" of which Raphael spoke. Further, with those workers they praised, the importance of divisions demarcated by grammar, cultural capital and other life chances, faded. Here, clients and workers understood what the other needed, and worked to co-create one another's presentations, resisting together their shared but different stigmatised status.

Conclusions and reflection on clients' perspectives

Olivia and I had a conversation about her role—and those of other clients—in training. She described a conversation she had with a case manager at Hillcrest. The manager was "*trying to convince Olivia to 'do them a favour'*" (Fieldnotes) and accept support from a once-rejected worker. When I reflected on this, I was reminded of the same organisation's "*lolly jar*" approach, their seeming casualness with rostering, their travel policy that left workers out of pocket, and their preparedness to not replace Ann-Marie and thus deliver the hours her former clients had been assessed as needing. I recorded my reflections:

Olivia is not there to do them favours and nor is she acknowledged (explicitly) as having a training role. Perhaps this was [the case manager's] way of asking Olivia to relax her requirements. When we talked about this, Olivia described the practice—which Brianna exemplified—of putting up a hand (exactly as Anita had described Sheree as doing) which says "Don't open your eyes to the human. Sweep emotion and pain and mess under the carpets and carry on". Olivia, on the

contrary, said "better to look very closely at that emotion and mess and humanity, see it clearly and then carry on". (Fieldnotes)

Olivia was naming care not as the 'professional' delivery of instrumental supports, constrained to deny human complexity and the visceral, but as diving into that "*mess and humanity*" and carrying on. I was reminded of Anita's remark: "*We're all human, it all happens to us*", and the other remarks workers had made that acknowledged what they shared with clients. Its opposite, denial or suppression, could lead to neuroses, to anger, to depression, with concomitant risks to both workers and clients.

It was clear that clients and workers were doing considerable work to establish an identity as competent and ethical people. Clients seemed to want to counter discourses that construct aging and disability as tragedy, failure, and loss; workers showed how different they were from colleagues or systems that were cruel, inefficient or de-personalising.

In the next chapter, workers' and clients' experiences of interactions with one another draw the results reporting to a close. There, the mutuality of care and practice is examined from within the client: worker relationship.

Chapter 7.

Findings—The self in interaction

I assume the proper study of interaction is not the individual and his psychology, but rather the syntactical relations among the acts of different persons mutually present to one another. (Goffman, 1967, p. 2)

Introduction

Interactions are the subject of this, final, results chapter. In support interactions, each person could present or sustain a self that was congruent or “internally consistent” (Goffman, 1967, p. 6). Clients and workers were doing considerable impression management work to establish an identity as competent and ethical people; they also performed emotion work to “sustain the outward countenance” (Hochschild, 2003b, p. 7) that would enable encounters that could maintain those identities. These tasks were made more taxing by how clients and workers were constructed in public discourses (see Chapter 4), and in some organisations. Clients wanted to distance themselves from marginalising constructions of ageing and disability as conditions of tragedy, failure, and loss. Workers showed how different they were from colleagues or systems that were—or were constructed as—cruel, inefficient or de-personalising.

So far, three themes have been central in the analysis of interview and observation data. These themes—Presentation of self, Performance, and How participants spoke about one another—paid attention to the individual’s experiences: as worker, as client, doing work and perceiving and responding to the other. But the significant work done by clients and workers in the presentation of self and the maintenance of face *for and with one another* called for a separate analytical theme about the self in interaction: Co-constructing

meaning. It was evident that clients and workers relied upon one another. Their interactions could “feel good” when they established or sustained a self that was “better than [one] might have expected” (Goffman, 1967, p. 6). But the actors could also “feel bad” or “feel hurt” when their “ordinary expectations [we]re not fulfilled” (ibid.).

Interactions were revealed in the participants’ descriptions, the photo-voice data and through observations.

Co-construction

Workers’ backstage instrumental work supported clients to prepare for frontstage performances. Clients wanted to “feel good”, to present a self that was congruent with their ideal, competent identity. Sally wanted to be able to go to the shops when she chose, rather than still being “*in her jammies*” at 11:00 a.m., Nicko wanted to behave appropriately at social functions, and Erica was learning how to catch the bus to and from work alone. When workers succeeded in sustaining such performances, and in completing the tasks of their role, they too could “feel good”.

But emotion work was needed. Workers adjusted their mood and approach to suit the interaction and client. They managed their emotions in order to “sustain the outward countenance that produces the proper state of mind in others” (Hochschild, 2003b, p. 7). The ‘proper state’ was one that was receptive to the workers’ presence and tasks; it enabled workers to perform instrumental tasks competently, and sometimes better than other workers. Hence, they were able to present their ‘internally consistent’ self as compassionate person and efficient worker. Clients, too, were doing emotion work. They prepared themselves for interactions, and worked to “sustain the outward countenance” that would mean that workers could be at ease and provide support in acceptable and enabling ways.

Meaning was constructed in workers' and clients' practices, but the success of the endeavour—and what meaning was co-constructed—was far from universal.

I observed and was told about interactions between the dyad members and between workers and non-participant clients. Photo-voice material added another view. From these data, characteristics of client:worker interactions were identified. Interactions could “feel bad” and be disabling, or “feel good” and be enabling. Between these two poles were encounters that had both disabling and enabling elements, and there was a link between the sorts of ‘verbal statements’ workers made about clients (Chapter 5), and how enabling or disabling their reported and observed interactions were. Figure 7.1 illustrates this link.

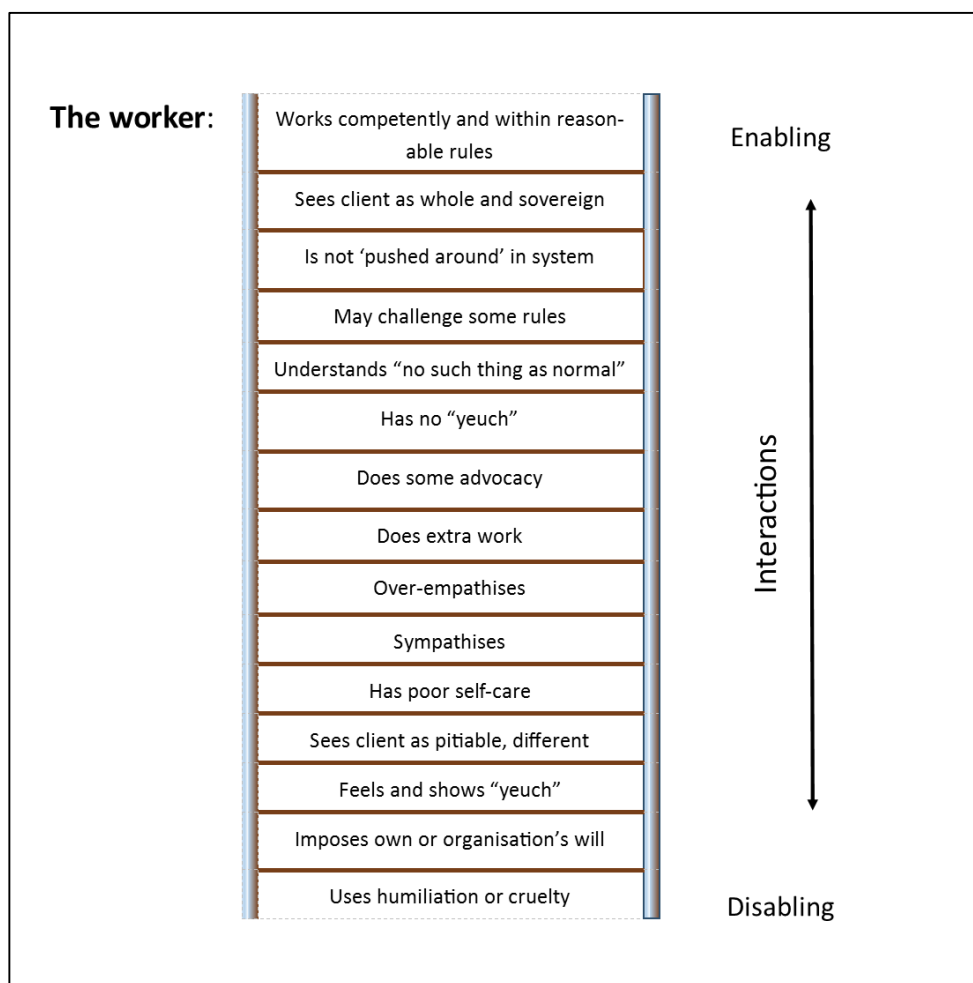


Figure 7.1. Characteristics of enabling and disabling interactions

Most observed and described relationships did not fit into an all-enabling or all-disabling category, and all had started between the two. At the beginning of the support relationship, worker and client did what was needed in order for support to be delivered, usually with good will, and bounded by policies and rules of the provider organisation. From this start, the actors' interactive performances drew them closer to enabling or closer to disabling one another.

The important part played by organisations—whether community or residential provider—was again apparent in this final analysis theme: Co-constructing meaning. Organisations set the tone for the relationships and influenced what happened next. Most of the workers and all the clients gave examples of ways in which employing/providing organisations shaped their experiences and performances. But organisations, like all participants, were working within a much larger construction in which disability and those touched by it were stigmatised (see Chapter 4, and, e.g., Fealy et al., 2012; Fine & Glendinning, 2005; Ranzijn, 2010; Shakespeare, 1997; Shilling, 2003; Turner, 1989).

Bounded trust

The first encounter between a worker and client is likely to be accompanied by anxiety. The worker is meeting a stranger who may or may not resist their performance of competence. For the client, the encounter may be their first acknowledgement of a new status as client, or it may be yet another experience of revealing their situation and impairments. Yet a form of trust exists, derived from the imprimaturs carried by formal assessment and the service provider organisation. The person with disability has the role, however reluctantly, of client (see Chapter 6), and workers carry links to authority, and perform tasks

which remind both them and the client of that link. I call this bounded trust.⁶⁸

Bounded trust is essential, but it is precarious because of the social construction of both roles. Neither workers nor clients can, for differing reasons, live up to the *Homo economicus* ideal (Houston, 2010; and see Danermark & Gellerstedt, 2004). In these circumstances, it is much easier for interactions to shift towards being disabling and “feel bad”, than enabling and “feel good”. How worker and client behaved and the emotion work they did determined the direction of the shift. Further, life chances and organisational or other social supports played important roles.

First encounters

Two first encounters demonstrate both the precariousness of trust and the centrality of reflexivity and emotion work in creating enabling, “feel good” interactions.

I was present when Anita came to work with Evelyn for the first time.⁶⁹ One of her favourite support workers had recently resigned and Evelyn knew she had to get used to someone new. The rostering clerk had let her know that Anita would be arriving, and Blanche had told her “*that I will like [Anita], because she’s lovely*”. Evelyn was nonetheless nervous, and had worked on her own presentation of self by having done all the housework. What the rostering clerk had not told Evelyn was that Anita would be bringing a student with her. When the two arrived, Evelyn was surprised, but—managing her emotions—

⁶⁸ This is related to but different from Debra King’s (2007) notion of bounded emotionality, which describes a balance between emotional and rational modes of care. As King depicts it, “While the emotions required to engage in these sorts of activities are recognised and valued, they are not given a free rein. Emotions are bounded by the intersubjective constraints required to ensure that individuals respond to others within the organisation in ways that sustain the organisational community” (p. 207). King’s concerns are focused on organisational behaviour and are not therefore central to my thinking.

⁶⁹ There was a surprisingly large number of such unexpected opportunities to see inside support interactions. Neither Anita nor Evelyn (whose dyad partners were Sally and Blanche, respectively) knew that the other was part of the project, and did not ‘give the game away’.

remained “*quiet and polite*” (Fieldnotes). Anita, unaware that Evelyn had not been asked about having the student present, was warm and cheerful. She made complimentary remarks about Evelyn’s dog and then offered to make a cup of tea and she and the student went into the kitchen. Evelyn and I finished our conversation and I left. Then Evelyn cut short Anita’s visit.

I asked both Anita and Evelyn about it later. Anita had detected Evelyn’s nervousness and reflected on the process from Evelyn’s point of view:

If they’re a new client to you, [...] perhaps they’ve built up a relationship with the support worker before, and she’s gone. So, they’re not really wanting someone new to come in; they don’t particularly want to get close, ‘cause they got close to that one and they moved her on ...

Evelyn told me she had been “*put out*” by the failure of Hillcrest and then of Anita to gain her permission for the student to be present. Despite Anita’s warmth, and the tick of approval she had from both Blanche and Hillcrest, Evelyn’s bounded trust was damaged. The following week, Hillcrest compounded the damage by not letting Evelyn know that Anita was unwell and would not be coming. The encounter had not enabled Anita or Evelyn to present a competent self.

The first encounter between Olivia and Joanna was more successful. Joanna had arrived, knowing Olivia’s age, that she was partially sighted and that she used a walking stick. Joanna jumped to a conclusion: when the two went shopping, Olivia would need her to help carry the bags. Her assumption was wrong. Joanna “*went to help Olivia out of the car, and picked up her bag*”. Olivia’s reaction was instant: “*she grabbed it from me and she said, ‘No. I don’t need help!’*”. Stopped in her tracks, Joanna thought, “*‘Okay—you don’t need help; you’re very independent. I’m just here to support you’*.” She “*took a very much back step*”. From there on, Olivia “*directs me. But I’m there, if she needs me*”. Joanna, already aware that “*you have to be different with every single different person, ‘cause they all have*

different needs", had seen and adjusted to the self Olivia wanted to present.

Joanna's reflexivity in response to Olivia's presentation of competence made for a "feel good" encounter.

How readily the worker and client adjust their performance scripts and the emotion work they do were important in how the interactions developed from their start in bounded trust. A third actor—the organisation—played a part.

The role of the third actor: The organisation

Organisations bring worker and client together. They set out to create an effective interaction in which the worker performs their part and completes the necessary tasks, and the client's needs are met. But things like the failure to gain Evelyn's agreement to have a student visit, and not letting clients know when workers were unwell, influenced clients' acceptance of workers. Little attention had been paid to either Evelyn's or the worker's needs by case managers or roster clerks. In Chapter 6 I reported that such failures were frequent: many clients spoke of poorly-prepared workers arriving, and of the failure of provider organisations to address their concerns. These failures disabled both worker and client. There was, Joanna thought, too often "*absolutely no consideration for people's lives and how [organisations'] decisions affect their lives*".

Reminders of boundaries: Surveillance

Isn't that funny—that, um, the model of the service provider can affect social connections between clients and workers? (Laurence)

There were other ways in which organisations and institutions shaped interactions. They stated their opposition to clients and workers forming personal connections and had policies and practices that were reminders of the boundaries around trust in the service encounter. One reminder was the "Communication Book" and its equivalents. Community-dwelling clients typically play host to a folder or notebook which may include support worker

rosters, details of case manager or other provider contacts and policies, personal plans, and a section where workers may make notes. Here, workers *“just write if you need something for the next [...] support worker going in”* (Anita), or to give family members relevant information. The broad intention is to ensure a shared understanding of the client’s state and the required tasks, much like the hand-over process between shifts in hospitals or residential facilities. All but one community client in the study had a version of the communication book, and all those who talked about it—whether client or worker—had a somewhat ambivalent attitude to it. The book and other reporting means were reminders of the surveillance operating in care and support work.

Several workers felt that making notes or reporting about clients was intrusive. Vic often completed the reports required in his community disability support role *“at home. I never did that in front of them; [...] I felt that would be unfair to them to see that”*. Since *“some clients read them and feel a bit intruded by it all”*, *“you do have to be careful what you write”* (Stella). Stella, like Vic, recognised the difficulty of maintaining trust while also ensuring safety. She tried to avoid offending clients by writing notes or telephoning case managers *“when I get in the car. You know, it’s—people’s dignity is really important to me”*.

These intrusions and semi-secretive reports could mimic unwelcome surveillance and reinforce the bounded nature of the trust possible between workers and clients—especially when clients were unable to read. Gerry and Erica, for example, are effectively excluded from checking on or responding to what is being written about them. This cast them as incapable, subordinate others (who were, at the same time, being pushed in other ways to ‘normalise’). For Gerry and Erica, as well as other community and facility clients, reports were also physically inaccessible, being kept by case managers or coordinators. Gerry’s personal plan, which was intended to be developed and adjusted by him, his parents and case manager, was fetched from a locked office in their

group house to show me.⁷⁰

One of the other functions of the book—or its electronic equivalents—was to record whether workers had carried out their tasks. Workers and/or clients signed the book after each service encounter to verify that the work has been done and the rostered time spent. Thus, workers too were being watched through the communication book.⁷¹

Clients were either mildly cynical (Evelyn, Raphael, Sally, Winifred, Bill), or openly hostile (Laurence) about the book. When I asked Winifred whether she had a communication book, she replied in a conspiratorial tone, *“Oh, it’s never been looked at”*. Then she reported that a worker, who was going on holidays, had written *“one and a half pages of what she did”* to orient the replacement staff member. This effort appeared to have been wasted, as the *“little lass that came to replace her [said] ‘Oh—mmm, mmm. Oh, mmm’, put it back in the drawer and that was it!”*. This matched Joanna’s experience of a replacement worker ignoring a clear note about a client’s need for a particular beverage. Evelyn smiled about book entries like *“Morning support—cut toes nails”*, which seemed *“silly”*. And Raphael joked about the whole process, reading out an entry in a patronising tone: *“Raphael enjoyed breakfast”*. Raphael’s amused cynicism was only a faint echo of Laurence’s vehement dislike for the book. Having described how a

⁷⁰ I was disturbed by the unconscious way in which the worker put the documents on the table to show me. My fieldnotes record:

I felt a little like an intruder in Gerry’s life here [...] there were photos of other people who are not in the study; what if I recognised them? [...] not sure why this bothered me [...] probably because if there was someone I recognised and didn’t expect to see, I would know something they hadn’t shared with me on purpose ...

This unease persisted despite my having asked Gerry and Erica for permission to look at the plans. My fieldnotes record several other internal wrangles I had about what to do in such situations.

⁷¹ The replacement of the book with smart-device timekeeping and roster notifications increases surveillance over workers. The possibility of clients signing off when workers have attended for less time—a phenomenon which is discussed briefly later—is curtailed when the tagging capacities of electronic systems are operating.

particular worker (Sonia) was over-familiar with him, Laurence told me that *“she even, she even wrote in the communication book, ‘Laurence had pizza tonight. He coughed. He coughed and choked’”*. Laurence was angry, saying *“I didn’t choke. I, my muscles don’t work and when I eat, sometimes; the muscles just react”* (and see Shakespeare, 1997, on objectification). Sonia’s note recorded her response to Laurence’s experience; it would be read by others and shape how they perceived him. His own knowledge and understanding—his expertise about his life—had no place in the book. He was being disabled.

Communication between workers and between workers and case managers can enable the day-to-day or week-to-week needs of clients and workers to be shared, thus ensuring continuity of support and tracking clients’ well-being. But the communication book was seen as either mildly or significantly intrusive.

Between bounded trust and “feel bad”: Institutionalising and disabling practices

Sign-tokens of “feel bad” interactions

Communication books, reports and file notes can infringe on clients’ sense of autonomy or create alienation—particularly where their trust in the organisation is fragile, or their agency weak. Evidence of surveillance intervened in relationships, and implied that neither worker nor client is capable of running their lives and having ethical ground rules. A net of institutionalisation is cast over clients (see Goffman, 1961a, in which he identifies the characteristics of institutions) and workers.

Clients and workers both complained about institutionalising—and disabling—practices. Several workers spoke of tasks that positioned them in surveillance or policing roles, and many were perturbed by what they saw as depersonalising or institutionalising rules. Vic, for example, talked about the requirement that

he fill in “a log book for James’s [puzzle activity] [...] Because ‘we’ think he was using it too often”. Vic disagreed with this recording; to him, doing puzzles was “*how James relaxes. I come home, I watch the TV or put the computer on [...] And he wants to come home and do his [puzzles] ‘cause he forgets what’s on the telly*”. Norah spoke forcefully about her dislike of the scheduled nature of life in Cliveden, with its regimented jollity and tight morning routines. Ruby had disliked imposing the sort of regimentation Gerry and Erica experienced in their group house, where they “*wake up in the morning [...] at six-thirty. And I go to bed at eight o’clock*” (Erica). Laurence was in bed by 7:00 pm, his day shaped by the restrictions of rosters. All those people who had worked in residential facilities felt similarly disempowered by the regimentation. That many of them made the same, rapid chopping hand gesture while describing morning routines in facilities was striking. Jai used the word “*commodity*” to describe how he felt residents and workers were seen by the organisation. All participants—in facilities or the community—disliked the time pressures, anonymising practices, and scheduling of lives.

Ways and places of living are “the most powerful sign of the self of the inhabitant that dwells within” (Csikszentmihalyi & Rochberg-Halton, 1981, p. 123). They represent “the accomplishments of the owner’s self” (ibid., p. 130). Institutionalising practices compromise this accomplishment. Most workers in the study were aware of their own “*invasion*” (Blanche) and wanted to maintain clients’ sense of home. But invasions still happened. Raphael said that most support workers thought of his house as having “*a revolving door*”. I watched this play out during a visit: first there was a delivery from a pharmacy employee, then a worker came to help Raphael take some medication. Each person knocked, but didn’t wait for an answer. As he said, sarcastically, everyone thought “*Just walk in—he’s always there*”.

Smoking, drinking alcohol and sexuality were other areas where clients’ choices

were reduced. Joanna, Tilda and Lilla spoke of being expected to enforce rules imposed—in one instance by a client's son and in the others by senior facility staff members—to curb support recipients' smoking or drinking. The son had imposed a smoking ban on his mother, though Joanna commented that were the client's husband still alive, *"she would have the cigarettes"*. Workers disliked such *"sheltering"*: Leonie argued against the *"wrap[ping] people up in cottonwool"* that often flowed from the narrative: *"This has happened to them, and we mustn't let anything else happen to them, so they're actually not allowed to live life"* (Leonie).

A sexual life was put out of reach by some organisational practices. Vic told me of several couples whose contact in their residential facility was restricted at the behest of parents or family members, and Erica told me she did not *"like Family Planning. No. I don't want to go—never again"*. The rules that Erica said were *"not fair. That's not fair for my—ah—friends"*, were about *"who's appropriate to cuddle, and things like that [...] Stranger Danger"* (Sharon). Erica had been told to curtail cuddling. This rule had been imposed as a protection (both of Erica, and from Erica—see Banks, 2016). Sexual abuse is a present danger for people with disabilities (Block, 2000; H. Brown, 1994; Saxe & Flanagan, 2013), and protection and risk minimisation are important.⁷²

All clients had experienced institutionalising practices, and disliked workers who imposed their will (or the will of the organisation) and treated them as *"a bit of paper"* (Brian). Clients deeply resented workers who ignored their different habits or ways of living and treated their homes (including in residential facilities) simply as a workplace. They were alluding to the need for workers to not disrupt the congruent, historical identity of the client, through instrumental, institutionalising practices that paid little attention to individuality.

The support encounter is an automatically risky interaction, where each

⁷² Though, as Dr Yarrow Andrew (pers. comm., 2015) suggested, imperfect sexual or romantic experiences are part of an ordinary life.

person's presentation of self is precarious. While surveillance, policing and institutionalising practices can reduce risks to safety for both people and ensure quality, they also disrupt clients' and workers' autonomy and can shift interactions towards being disabling.

Inattention

Inattention was another way in which clients' presentation of self was put at risk. All forms of inattention shifted relationships between client and worker towards disabling and "feel bad". Worker inattention may be a form of self-care—especially if clients treat workers as sponges for anger, pain or sadness—and it may be innocuous (and indeed protective of both people if we consider it as an example of 'civil inattention' in action—Goffman, 1963a; Longmore, 1985). But the failure of workers to try and understand what people were saying (see Chapter 3), or to give them focused attention, was disabling. When Gerry talked about what he did at work I did not immediately understand. His personal plan listed some of the tasks, so I read them out, and gained clarification from him. Sharon then said, "*That's what you do!*". Despite working with him for some time and being involved in his daily preparations, she had not known what he did at work. It was also clear that the workers Edwina and Stella did not understand everything their dyad partners, Laurence and Raphael, said in their interactions. Interactions in these two dyads, and between Blanche and Olivia, demonstrated the subtly disabling effects of inattention. I focus here on those between Stella and Raphael.

Stella and Raphael—kindly inattention?

Raphael and Stella's interactions were unequal; they appeared stilted and were infused with Raphael's almost taunting sarcasm and Stella's thinly-disguised pity. In interviews, each spoke of the other with kindness and seemed to wish one another well, but observations revealed tired acceptance, bemusement and

mutual isolation:

There was banter between them, as well as Raphael making smart remarks, to which Stella either did not respond or responded with a smile. She did not seem to necessarily be getting on the wavelength of the remarks he was making, which I suspect he makes whether someone is watching or not—a sort of talking past one another that he is enjoying and might be to retain agency [...]

So, from the kitchen to the lounge is a little distance, but as well, Raphael had the radio on ... This made it fairly difficult to hear Raphael and [for them] to converse in any flowing way. So, at one point, Stella called out, “Can’t hear you, Raph”. Her tone was a little like one might use to say “Talk to the hand”, or the tone adopted when one is waiting for a child to say ‘please’. A sort of slightly in charge and in control tone, but not impolite or unpleasant at all. (Fieldnotes, observation)

Stella’s first task when she arrived was to make breakfast, a chore both acknowledged was a ritual rather than a necessity. “*The reason we have the ritual*”, he said, “*is because [...] the Sunday worker comes about nine-thirty. By nine-thirty, I’ve long since had my breakfast. So I just give her a jab*”. The “jab” was part of their interaction style. Once she had made it, Stella brought Raphael’s plate of toast over and put it on a tea-towel on his knee, then crouched and started talked to him. Then, she realised that:

she had not given Raphael a tray for his toast, so she reached for it (it was on his left hand side, tucked between the chair and the sofa). It’s one of those trays with a sack of polystyrene balls under it, to make it stable [...] On the matter of the tray, Stella apologised for not putting it on his knee when she brought the toast. He seemed a bit pissed off about this—and made a remark about needing to train people. It was not unkind, but was obviously something she should have done. (Fieldnotes, observation)

Balancing the plate of toast on his knee was very difficult for Raphael. It drew attention to his impairment and disabled him.

Stella then asked whether he wanted the vacuuming done. “Yes, please” (in a

ticking items off a list tone). Stella started vacuuming in another room, but *“the vacuum cleaner is quite whiney and noisy. Raphael is eating his toast. I can’t hear the radio, and imagine that Raphael can’t either”* (Fieldnotes, observation). She continued to vacuum—around chairs and under the dining table, but in a sort of cursory way. She commented to me, *“I know it looks like slack vacuuming”*, but that the rules forbade lifting furniture. Then, she vacuumed over towards Raphael. Here, she asked him, *“Shall I vacuum around you, Raphael, or are you going to hop up?”*.

Stella’s manner was air-hostessy—bright and breezy, a little oblivious, but she seemed to want to make a connection with Raphael. Throughout the visit, she mostly came over to Raphael when she wanted to talk to him, crouching on the floor in front of him, so that her head was lower than his. She put one hand on the chair seat beside his right knee, for balance. Each time she came over to talk with Raphael, she either sat opposite him or adopted the crouched position near his chair, so as to make eye contact.

As the visit progressed, Raphael continued to be somewhat sarcastic and mocking. But, towards the end of the hour, something changed. Stella had become more and more agitated. She had done all the things that she needed to do, her several efforts to make conversation had been awkward, and now she seemed to be looking for something to do.⁷³ She went over to Raphael and asked if she could straighten out the blanket which lay over his chair. He replied with the usual, *“Yes, dear”* and she turned to me saying *“He says it when I’ve been too bossy”*. Raphael’s immediate rejoinder was *“Come back when I’ve got a real carer”*, then softened it slightly with, *“They all get the same treatment”*. She fussed over the blanket, trying to straighten the parts she could get to. My fieldnotes continue:

⁷³ The impact of my presence cannot be discounted. Stella and Raphael were almost certainly both performing for me, conscious of the impression they wanted to make.

And she asked if he had scissors so she could trim off some frayed ends. The mood between them had become more and more edgy and picky. But then she came quite close to him, adopting the same crouched position as before, and touched his knee. She looked him in the eye, and she quietly asked if he could get up, so she could properly attend to the blanket. She asked if he wanted a hand up. He rejected it, but nicely, and she stepped back. He got up. This was an interesting moment for me. For all the rest of the time, Raphael had seemed physically still and perhaps frozen. Asked to move so that Stella could straighten the cloth, he pretty much bounded out of the chair and walked away to give her the necessary space. Stella shook out the cloth and straightened it, laying it back on the chair with no creases. Raphael came back and sat down again. (Fieldnotes, observation)

This moment of touch was striking. When I asked each person about it later, Raphael made amusing and self-mocking comments about how much Stella liked him, and Stella took some time to respond. She began by saying that she did not “*generally touch male clients at all*”. Then, she said that she, “*ah, I just, um, I just have this compassion for Raphael. Just wanting him to let him know that I care. I just thought that I, just that bit of human touch is important. Mmm. To know that he is special*”. My own interpretation of the moment of touch is different. I think Stella was trying to shift the atmosphere to one in which his snarky remarks were not present. She wanted him to see she was serious, that she cared about him (and about her self) and that she wanted him to stop mocking her. In bounding out of the chair to help her, Raphael signalled that he was prepared to allow that performance.

Raphael, despite his sarcasm, had described Stella as kind and she had given me evidence of his warmth and generosity to her. She was pleasant and busy, yet did not really pay attention to him, or try to understand his sometimes muffled speech, and seemed unaware that her noise was intrusive. She later told me she found it hard work conversing with him. It was partly a lack of common cultural ground, but she did not quite trust him, since “*he does like to*

have a bit of a chat about the other carers" which made her wonder "*what's he saying about me?*". Perhaps the most significant thing that she reported to me was that she felt some pity for him, since his illness had been so debilitating and had been accompanied by the collapse of some important relationships. This pity permeated some of their interactions.

Stella's sincerity was clear. Yet her acts signalled a stigmatising way of thinking of him—based in pity—that positioned him as different and other. He had also positioned her. Interactions between them were infused with traditional gendered behaviours. Though they had only some choice in the matter, his performance resembled that of a patriarchal husband, and hers a submissive, domesticated wife. As well, there were cultural and class distinctions evident in their interactions.

Summary: On the edge of disabling

In these in-between relationships, support interactions were efficient but the emotional dimensions were problematic, and peppered with inequalities. There was no mutual co-creation. Raphael's sarcasm diminished Stella, as did his evident lack of need for some of her contributions. Stella disabled Raphael with her inattention to the tray, her noisy (and pointless) vacuuming, and her pity. Stella did the vacuuming, and the pity, because it was part of her presentation of self as an effective, competent and caring worker. But she was at a loss with Raphael. She knew that several of the tasks she was there to do were not needed. If she were there for a social visit, that seemed not to work. There seemed little she did that Raphael valued. His intellect and resistive manner meant that he did not respond to her in ways that would enable her desired presentation of self. She was therefore unlikely to be able to co-create his desired presentation of self, and her own performance remained incomplete. Thus, both people were devalued. Dyad members in this category were seeking—perhaps ineffectively—ways to resolve the tensions. When she

stopped and put her hand on his knee, I argue Stella was working to re-establish equality in the interaction; he complied—at least for the time being.

Sometimes, in these relationships, workers reported cajoling, badgering or manipulating clients or residents in order to get the job done. Edwina, for example, was directive with Laurence several times:

“Time to settle down”

“Plate to the sink” [jokey bossy]

“Don’t drink it all at once”

“You’re giving me a headache with your cryptic jokes” [rolls eyes]

“You just confuse the issue—just let me do it; much easier”

“How long were you on the computer?” (Fieldnotes, observation)

These approaches risk negating the recipient.

But demeaning interactions were not one-directional. Stella, Joanna, Blanche, Tash, Shirley and Brian all gave examples of clients who *“treat us like the help”* (Shirley). Blanche contrasted the gratitude expressed by many clients with *“people [who] don’t even say please or thank you—they just [...] treat you like a servant sort of thing”*. People who had this master:slave attitude *“make life difficult”* according to Tash, who described a community client as seeing *“support workers as his slaves, and he loves it”*. Being treated as servants or slaves was stigmatising.

Experiences that were institutionalising, negating or stigmatising shifted relationships of bounded trust towards entrenched non-egalitarian, disabling patterns of behaviour. Clients could be treated *“robotically”* (Laurence) or *“like an invalid, [...] like a child”* (Norah). Forms of address were part of this positioning.⁷⁴ Sometimes, aware of the shift, one or other person worked to

⁷⁴ Viz. use of the epithet ‘girls’ for middle-aged support workers; and the growing evidence of the negative health impacts of ‘elderspeak’ (there is a growing literature on the effects of ‘elderspeak’; see Cunningham & Williams, 2007; Dobbs et al., 2008; K. Williams, 2005; K. Williams, Kemper, & Hummert, 2004).

bring the interaction back towards “feel good”, as Stella had when she touched Raphael’s knee.

“Feel bad”, disabling and unequal relationships

Where little or no effort was made, or those involved lacked emotional resources, clients could resist particular workers, ask them to leave early, or reject them altogether. Tilda reported experiencing all three. Such experiences dominated her descriptions of work, and it appeared that in such interactions, neither she nor the resident or client was able to present their chosen self. I report two examples.

Tilda and Kostas—A battle of wills

I did not observe interactions between Tilda and Kostas, but she (and another participant) described him to me. Of all her community clients, Kostas was the one she had known for the longest. Kostas often used a motorised or other wheelchair to get around, just one of the things about him that seemed to annoy Tilda. First, he had too many:

He’s got three of them. I feel like saying, ‘Oh, it’s nice to have the money to have, buy, all them’. Now he’s talking about buying something else. He’s got one he uses at home, and he’s got one that pulls apart to go out and about it.

This annoyed her not only because of the access to resources it signalled, but because it was awkward for her to handle. The first time she had to dismantle the chair, “I said to him, ‘I don’t know if I want to do this. It’s heavy; it’s awkward to get in and out of my car. If I scratch my car ...’”. She also thought he should be spending his money on taxis (rather than pain medication) and thus relieve her of having to manage his wheelchair. She responded to his complaints about the pain and difficulty he was having moving by saying, “Well, if that’s the case, we don’t go anywhere. If you can’t stand to get into that chair, you cannot go out and use it”. Each such remark was a reminder to Kostas of his situation.

Aside from these difficulties, she and Kostas also argued about Tilda's role:

*He said to me, he said, "I'll go down to the shops, and you bring the car". "No".
"I'll go down the footpath, you bring ...". "No, Kostas. I don't, I am not someone
who just goes shopping with you, or coffee", I said. "I have a duty of care to make
sure that you are safe. I am not allowing you to go down to the shops in your
scooter, without me beside you" [tone is strict—bordering on bossy].*

Here, Tilda was 'sticking up for herself' but also not treating Kostas as capable or competent.

The two also clashed over money and support. Kostas was incensed, for example, that the cost of any additional hours of support he wanted would be much greater than just Tilda's hourly rate.⁷⁵ Then, when he asked about the chance of being assessed for a more generous support package, she told him that *"somebody has to die for you to have that sort of package"*. This prompted a determined fight back from Kostas in which he was insulting about the coordinator at Crescent. Tilda felt personally offended and, unable to manage her emotional response, said so. She appeared to have few resources with which to respond when residents and clients challenged her.

Neither Kostas nor Tilda seemed to be enjoying their contact. Both seemed to be resisting, but tolerating the unpleasantness. She described him as being *"quite stubborn"*, and their long association had not led to more understanding. She was domineering; he was demanding. They talked past one another. From her reports, it seemed that Tilda was unwilling or unable to imagine Kostas's perspective or needs. In our interviews, she often aligned herself with her employers,⁷⁶ and presented herself as a good person, unable to lie, loyal to her

⁷⁵ Service costs are substantially higher than the \$18–22 per hour the worker receives, as they cover both the worker's wage and the corporate 'on-costs' of service provision like rostering, case management and coordination.

⁷⁶ Tilda's loyalty (as well as remarks made by Bill and Olivia about provider organisations) prompted me to consider the role of strong and weak ties (Granovetter, 1973). Office staff and support workers in residential facilities may develop strong ties to the organisation and one another, while support workers in the community could become more strongly tied to clients.

employers, and subject to the whims of greedy, selfish or unreasonable others.

Tilda's interactions with residents at Shore View — the fairly prestigious residential aged care facility where she worked half the time — were similarly fraught. Tilda described Beryl, a former headmistress, who was now experiencing severe dementia, as being *"very brutal"*. She described one night when Beryl was *"making a fuss"* (*"Oh, you're starving me—you don't care!"*) about being hungry. Tilda responded, using Beryl's accent, *"'I can't be bothered, Beryl. I don't care' [Tilda acknowledged that she was mocking Beryl] 'I can't be bothered' [more accent]"*. Beryl then told Tilda, *"Oh, you're evil"*. Tilda's *"humour"* had not worked; Beryl was *"just a mouthful of verbal diarrhoea and it just got to me"*. She asked the RN on duty for support, saying, *"'Either she goes to her room or I walk out with stress'. 'Cause I was just about to the point of tears"*. But support was not forthcoming; the RN simply advised her to not *"let it get to you"*. Tilda, unable to do so, was left to deal with the emotional aftermath: *"Well, I'm not a robot. I, I try not to let it get to me, but, you can only listen for so long and be called evil [...] and I know I'm, not, but it still wounds my heart"*.

Brian, Miriam, Lilla and Jai readily described some residents with dementia as nasty or even *"bastards"*, but they called on their 'client-whisperer' skills and weathered demanding or otherwise selfish-seeming treatment from residents. They saw outbursts as signals of particular needs and worked for engagement and good physical care. Tilda, though, seemed unable to see Beryl as a person experiencing the trauma, losses and deep confusion of dementia, and not

There was evidence in this study for this model. Some workers in residential facilities and administrators working in organisation offices ignored or played down problems residents and clients experienced. They may have 'looked away' out of loyalty and the sense of shared identity with one another, casting residents and clients as the other. Indeed, as Olivia suggested, it may be argued that the culture in some organisations relies on having means for avoiding empathising or even noticing the pain and suffering of clients. This is a weakness of strong ties.

simply a “*brutal*” person. Indeed, she added to Beryl’s trauma with her mocking and barbed remarks.

Tilda was both unable to satisfy Beryl’s (or Kostas’s) needs, and unable to feel satisfied with her own work and presentation of self. Despite the apparent advantage of being the provider of support (with the capacity that implies), Tilda’s actions and words were those of a person resenting their *lack* of agency. Work (and life) was a series of battles, like those with Kostas and Beryl. There was no fellow feeling or sense of a shared endeavour in her descriptions of working with clients, and the divide appeared to be at least partly along class or capital lines. Her responses (and some reported by Tash and Blanche) to residents like Beryl were very different from those of Brian, Jai, Lilla or Miriam. Was this because of their willingness to seek understanding of what motivated it? Or was it that they had the capital or resources for their own intact presentation?

Summary: Disabling, “feel bad” relationships

Face, according to Goffman, “is not lodged in or on [the] body, but rather something that is diffusely located in the glow of events in the encounter and becomes manifest only when these events are read and interpreted for the appraisals expressed in them” (1967, p. 7). The self (face) is created in interaction.

Interactions that were demeaning and stigmatising could disable clients. Workers who were inattentive, whose performances were robotic and detached, who mocked or humiliated, who visibly baulked at the “*yeuch*” or who kept their distance, looked elsewhere, or “*hosed off*” clients (see Chapter 6) all risked signalling a “spoiled identity” (Dobbs et al., 2008, p. 518) and “negative evaluation” of the client (p. 517). Such evaluations, as Dobbs et al. (2008) argue, “may become the core of personal identity” (p. 517) with clients or residents

accepting “being devalued” (p. 517), but suffering nonetheless. People who treated Laurence’s house as a work space, or were robotic and inattentive, made him *“depressed, not depressed, but I get on the borderline of being melancholy”*.

Workers and clients needed to pay attention, be reflexive and do emotion work.

Conversely, clients or residents who resisted the ministrations of insensitive or cruel workers may have been exercising agency and self-care. As well as seeking to maintain presentation of self as independent and capable, they also resisted experiences and people that were sources of irritation, discomfort or that disabled their presentation of self. The reverse was true for workers, whose presentation of self could be undermined by harsh or resistive clients, and inadequate personal or collegial resources and support.

Between bounded trust and “feel good”

Sign-tokens of “feel good” interactions

In “feel good” interactions, the regimentation clients and some workers disliked was absent; things were done in no obvious order and, although there was little idleness during service encounters, there was also no sense of haste. Things were tidy, but also particular to that place rather than reflecting an imposed set of rules. At two places I visited, for example, there were tables strewn or piled with papers and craft materials, left out to be taken up at any moment. Bill and Delia’s house was clearly much as it had been throughout their life together, and Nicko had crafted the home he wanted to suit the self he remembered and was re-inhabiting. In these and most of the other places I visited to observe the dyads, ways of living seemed to have been shaped only a little by the interpolation of support work. This naturalism or organic quality was present in those relationships that fell towards “feel good”. This was the case with Evelyn and Blanche, Anita and Sally, Brian and Bill, Winifred and Shirley, Nicko and Leonie, and Joanna and Olivia. For these dyads, Anita’s comment,

"You know—it's not about the floor", was apt; sitting down to "have a cup of tea and talk" (Evelyn) was an important part of the interaction.

Cementing trust was instrumental in shifting relationships from their 'bounded trust' beginnings towards being "feel good" and enabling. Such trust was, according to Brian, foundational: *"How do you possibly interact with somebody that you dislike, don't care for, or don't trust, or don't know [...]?"*. Trust was a descriptor used by Sally and Anita, Brian and Bill, and by Raphael when he talked about Brendan. Evelyn, too, had realised *"bit by bit"* that she *"could trust [Blanche]. Implicitly"*.

Trust was associated with participants' use of terms like *"mother"* (Joanna, Laurence, Blanche), *"grandparents"* (Jai), *"sister"* (Laurence, Joanna, Sally), *"brother"* (Vic, Edwina) and *"son"* (Bill, Vic) for one another. Observed interactions here could resemble the "fictive kin" relationships described by Outcalt (2013), with concomitant power swaps. There was banter, in-jokes, mutual concern and affection, and sometimes disagreement. Raphael reported several very funny 'routines' he and Brendan performed.⁷⁷ The sort of trust that was present no longer relied on the official signals of approval: the members trusted the relationship to continue and a level of candour to exist. To report on these relationships, I use the example of Evelyn and Blanche, whose relationship was very much like that between slightly combative sisters.

Evelyn and Blanche

Evelyn described her relationship with Blanche as *"Close. Reliable. Trustworthy. Ah, probably tending to a close friendship [...] Um, she'd do—I think she'd do anything for me"*. The observations and photo-voice data exposed some power plays within that trust.

⁷⁷ The warmth of this relationship was commented on, unbidden, by another worker in the study.

On the day I had arranged to meet Evelyn, she was expecting a support visit from Blanche.⁷⁸ We were talking when Blanche arrived:

The relationship between Blanche and Evelyn looked smooth. A sense that Evelyn was in charge, but Blanche was both "very accommodating", as Evelyn said, as well as quick and engaged [...] There is a slight sense that Evelyn is 'teaching' Blanche—a few times a complex word came up (one was 'anthropomorphising' in relation to [the dog] watching television with Evelyn in the afternoons), and there was a brief discussion between them about their habit of looking up words [...] Evelyn was highly aware of the words I used, and there was an edge in there of 'us and them' perhaps ... that Blanche might be in the them category? (Fieldnotes)

When I reflected on the meeting, I also noted, "*There were some power plays going on*" (Fieldnotes).

On another occasion, I watched as Evelyn and Blanche negotiated a small furniture moving task. Evelyn reminded Blanche to vacuum the floor where the shelves were to go and Blanche "*seemed faintly resistant*" (Fieldnotes). But, each made several light remarks about tidiness and they were considerate and attentive:

Blanche: Mind your hand.

Evelyn: I keep forgetting how weak I am.

Blanche: Oh, you are not!

Later, when we talked about my observations, Evelyn wondered whether they were "*bantering too much*", saying that "*sometimes it gets a bit overboard, I feel*". This feeling was compounded by her suspicion that sometimes Blanche "*was not listening*", when Evelyn told "*great long stories*".

Another note of tension crept into the observed interactions over 'the word book'. Evelyn, who had been tidying up the table, picked up a small book and

⁷⁸ Evelyn had already invited Blanche into the project. I checked that Blanche understood the project, gained her consent and then became an observer.

asked Blanche whether *“she is still interested [asked quite tentatively]”*. Blanche reassured her, and then *“Evelyn shows her the word ‘oxymoron’, and asks if Blanche knows what it means. Then she also shows her a brochure which she had from somewhere which has the title ‘Healthy Dying’”* (Fieldnotes, observation). Later, when I asked Blanche about the book, she responded, *“she’s a brilliant woman”*, then paused. Blanche said she wanted Evelyn to be able to show how clever she was, and had *“said to her, ‘Oh, you should’—‘cause she’s always looking up things in the dictionary—I said, ‘you should teach me some of these words!’ So then, we did”*. Evelyn would write the word then the meaning in the book and then Blanche *“had to do my homework and remember it”*. Blanche had been *“quite liking it”*, until it became a source of shame: another support worker *“popped in. And, she, Evelyn, made mention of this, almost like, like making me out to look like an idiot”*. Blanche decided they *“just won’t do that again. So we didn’t, until she brought it up again the other day, and I thought, ‘Is she doing that again, in front of you?’”*. Blanche tried to make sense of Evelyn’s apparent shaming of her:

I don’t know, ‘cause I wouldn’t imagine her to be nasty—but it just ... Maybe it was just me being sensitive, I don’t know. But, I just thought, “No, no”. It was just between her and I, we were doing that. And also, that makes her feel good.

Blanche thought that Evelyn had *“lost confidence in herself”* after her illnesses. She wanted her to feel proud of herself and frequently—as I had seen—responded to Evelyn’s *“I couldn’t do this without you”* remarks by saying *“Of course you could now! You’re good now—you can do all this”*. With the word book transgression, Blanche’s work to make Evelyn *“feel good”* had—temporarily at least—backfired. The book enabled Evelyn to present a particular competence, which Blanche encouraged, but Evelyn’s use of it to demonstrate that competence to me (and to the other worker) was a mis-step. When I asked Evelyn about it, she too had recognised this. Social class and cultural capital difference had interfered.

What their photos revealed

Evelyn and Blanche took 19 photographs about the work (the photo-voice methods is described in Chapter 3).⁷⁹ The images fell into two groups: photographs of instrumental, enabling elements, and those that were intrusive or demeaning. In the former category were pictures of the kitchen sink with the washing up draining, and of Evelyn getting her breakfast, for example. The images showed the strengths they saw in one another. Remarking on the photographs Blanche had taken of Evelyn in the kitchen, Evelyn said, “*She took one of me making tea, and she said, ‘This is the role reversal one’ [laughing]*”. She thought that Blanche wanted to show Evelyn’s capacity and independence. Blanche had also photographed Evelyn working on one of the intellectual hobbies she had, and Evelyn had photographed Blanche retrieving the hobby materials from a high cupboard. Evelyn had also photographed a plate of biscuits; she told me that Blanche was always careful with Evelyn’s resources and counted out only enough biscuits for the immediate need (Photo-voice image 1). This group of photographs depicted their respective strengths.

⁷⁹ As many of the photographs taken for the study included participants’ faces, only some were able to be reproduced here.



Photo-voice image 1. “Oh, so that was the biscuits, where they were counted out”

But other images hinted at less instrumental ‘stories’, and Evelyn and Blanche’s comments in the interviews showed that neither was happy with the results. At the less disturbing end, both women made body image comments. Evelyn worried that she looked *“enormous! Am I as big as that?”*, and Blanche responded to photographs of her saying *“Oh, fat guts [looking at side-on shot of herself] [laughing] Oh yuck! [very drawn out “yuck”] Suck it in next time. Yup. She’s just a bad photographer. She makes me look fat [both laughing]. Oh my god. Am I that fat?”*.

The next sequence of images appears to signal discord in their relationship. Three portraits, taken late at night, show Evelyn, heavily bandaged and in bed after skin cancer surgery. When I showed these to Evelyn her response was *“Oh dear, oh dear [Evelyn is sort of laughing and sort of sighing]. She wouldn’t stop photographing [sounds really like— ‘I tried to stop her’]”*. The event the photographs alluded to—the fact that Blanche had stayed over (unpaid) with Evelyn after the surgery—was an act of kindness. But Evelyn had *“got a fright that she came in with the camera”*. I commented that she looked *“very tired and a bit [whispers]*

pissed off”, to which Evelyn responded: “*A bit pissed off with her for taking so many!*”. Such exercise of power was mirrored in images taken by Evelyn. For example, Blanche was shown on her hands and knees, cleaning dog sick from the rug (Photo-voice image 2). Evelyn saw this as evidence of Blanche’s dedication and wish to make life with André as simple as possible:

Dear Blanche [...] has mixed me up —you know a squirt bottle [...] That gets the stains off. [...] She goes around every time she comes, not just on her cleaning day. She says, “Okay—now. Where was he?” She, I don’t even have to tell her now, she can see. [...] So that’s extra-curricular, I think.

Yet the posture was demeaning.

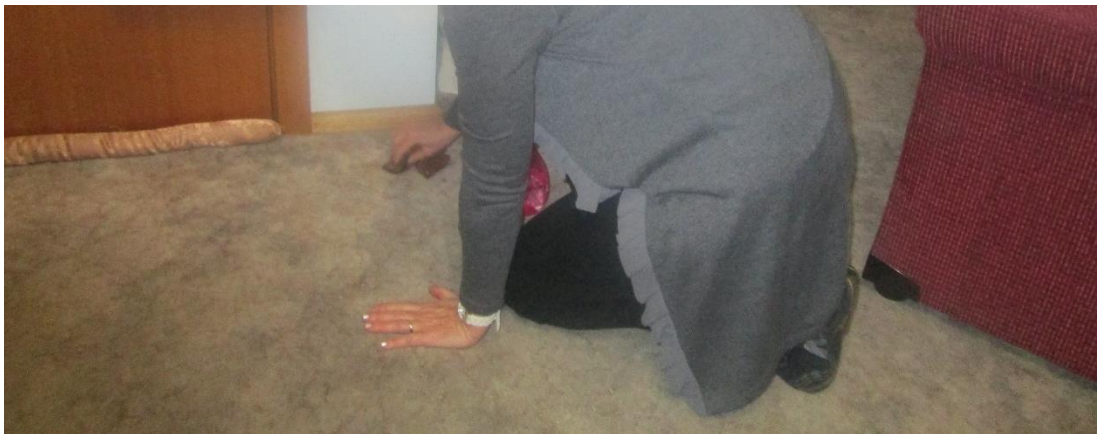


Photo-voice image 2. “She goes around every time she comes, not just on her cleaning day”

On photo-voice

Photographing one another in demeaning situations brought to light some dilemmas posed by such paired photo-voice. Power was being exercised through making potentially demeaning images. Further, sometimes Evelyn “*didn’t know she had the camera there. I did with that one, but I didn’t with these two*”. The two women had given one another general permission to take the photographs, but permission for individual images was less clear. Both Blanche and Evelyn seemed to have been careless with the other’s sensitivities. Both had

chosen to take part in this part of the project, and we had talked about the need to ensure that the subject consented to any photographing, but they had not kept to those rules. The resulting images captured things that the subject was aware of but may have been working to mask as part of their impression management. The data gathering technique itself had, as hoped, revealed the taken-for-granted or hidden, but had also undermined participants' impression management work. The same had happened when the audio-recorder brought Raphael's speech difficulties into stark relief, and when I worried that the photographs in Gerry's personal plan would breach the privacy of someone not participating in the study.

Interview and observation data from Evelyn and Blanche built a picture of mutual liking, and sisterly swings in power. Their views of one another were decorated with epithets like kind, resourceful and clever. But the photo-voice exercise—both the images themselves and how they were obtained—reinforced the observations of power plays. The interactions were not quite benign. In her efforts to present her intellectual competence, Evelyn had used her cultural capital and class advantages in ways that threatened a vulnerability in Blanche: her poorer life chances. And Blanche had pushed back, making images that displayed Evelyn in a physically vulnerable state.

Summary: Oscillating between enabling and disabling

Evelyn and Blanche's relationship was satisfactory and they liked one another. Like Stella and Raphael—and Anita and Sally—they had routines of interaction in which the power plays sometimes undermined the other's efforts to present a competent self. But, typically, each person seemed to want to remedy any difficulty between them. Each seemed to be shifting their presentation, reflecting and doing emotion work in order to sustain an important relationship. These characteristics were typical of relationships that oscillated between disabling and enabling.

Getting to “feel good”—Emotion work

People in the research dyads were working to maintain existing support relationships, and to connect with new support partners. Evelyn had spent a long time trying to warm to Ann-Marie, and Olivia, Jai, Brian, Miriam, Vic, Anita, Cornelia and Sally spoke of similar efforts they had made with unfamiliar workers. Anita had *“just clashed—right from the get go”* with Edith who seemed resistant and unhelpful. After one encounter, Anita rang the case manager, saying, *“‘She’s a fucking pain in the arse! [said vehemently]’, I said, [...] ‘She won’t even let me borrow her pen, ‘cause she’s on a pension’”*. Anita was unable to work effectively, and neither she nor Edith was ‘feeling good’. But Anita was in the habit of reflecting on interactions. She thought about Edith’s life, realising she had *“been on her own for so long; she’d had to be a really strong person to have survived that. And, I was coming in, [...] You know—she wasn’t having me come in and tell her what to do”*. Anita recognised Edith’s resistance as a form of maintenance of self, and now tried to mend the relationship:

The next time I went, I went to the bakery before I went, and I bought some date scones or something like that [...] And I said, “Feel like a cuppa?” “Hmm”. And I thought, “Please don’t say ‘Did you bring your own tea-bag?’”. [S laughs] And, ah, she said, “Oh, that would be nice.” And it started from there.

This interaction resembles the moment when Stella touched Raphael’s knee and his instant and willing compliance.

Anita, like many other participants, was frequently reflexive. These participants sought connection and did significant emotion work in order to change failing relationships, an act, one could argue, of enlightened self-interest. Jai talked about seeking connection with a resident, whom *“everybody didn’t like, and he was, quite grumpy, and he was very stuck in his ways, and, and um, and, ah, he was basically an old bastard [said in a loud whisper]”*:

And, by talking to the residents, I’m doing what I just explained—I’m trying to

learn about them. And for them to teach me something as well; to get something back, but also, so then you can make a connection. They know who Jai is. So they, you know, they'll remember you as well. (Jai)

Jai struggled to find something “‘to talk to this bloke about’”. His persistence paid off: he discovered the man was “*really into, ah, he was really into gambling, um, with the trots. And I thought—‘Oh, that’s interesting ... Like, tell me about trotting’*”:

And you know, as soon as you make a connection, there, there, any walls that they’ve put up to you as a health care provider, come tumbling down. And, you know, even the thing that they will, they hate doing—whatever it is—you can somehow get them around,⁸⁰ because you, because you, you’ve opened it up a little bit. You’ve taken a barrier down.

Jai’s next remark sparked an important moment in the study. It brought the themes I had been using to understand the intersection between practice and meaning in support together. He said, “*You’ve become people to each other*”.

Becoming people to each other relied on emotion work done by workers and clients. It demanded attention and reflexivity and it moved interactions towards trust and enabling.

Being people to each other

Raphael and Brendan

Raphael and Brendan were people to each other. Raphael’s stories about interactions with Brendan were about amusement, trust and connection.

Raphael did not invite Brendan into the project, because, “*First of all, Brendan won’t talk to you about me. He’ll talk to you about anything in general. Um, even if I gave him permission, gave him permission to talk about me, he wouldn’t talk about*

⁸⁰ I was frequently struck by the need for workers to have residents or clients do something they did not want to do, part of their policing role.

me". But Raphael continued to share stories that made the link between meaning and practice apparent:

Brendan helps Raphael dress in the morning and stacks the clothing in his closet in colour-coordinated piles. When dressing him, Brendan has Raphael stand in front of a full-length mirror and he asks, "How does that look?", and "How does that make you feel?" These were serious questions. (Fieldnotes)

Brendan was working to ensure that Raphael presented the self he wanted to present. Presenting Raphael's chosen self was part of Brendan's job. If he got that right, his own identity as a competent worker was shored up.

But there was another form of reciprocity operating. Raphael had told me that, with Brendan, discussion of "anything is possible". This freedom and trust enabled interactions like this:

Raphael said that he had had a long talk with Brendan recently. Brendan was pondering ... said he was 63, felt there were serious flaws in the organisation he worked for, and ... what was he to do? Had to keep working. So Raphael—whom he called 'Father Confessor II'—and Brendan talked it over and suggested that he "lighten up". Brendan had come back a few days later and said that Father Confessor I (his actual father) had given the same advice. So, asks Raphael, "What are you going to do?" Brendan: "I'm going to lighten up". (Fieldnotes)

Raphael had worked in a counselling role. Now, he was unable to work and his most frequent company was support workers. The competent self he had presented at work was mostly invisible. But he told me that Brendan and other workers sometimes asked him for advice, and in doing so they were co-conspirators in his presentation of self. In these stories, Raphael was "showing me/telling me that he is a good counsellor [...] But it also showed me that he is giving something to Brendan, which Brendan values" (Fieldnotes). The emotional support was reciprocal; Raphael felt Brendan would "go in to bat" on Raphael's 'team' if necessary; "You get the feeling I like him?". Brendan's matter-of-fact interactions with Raphael were very different from the soothing pity of Stella.

Joanna and Olivia

I observed one of the last service encounters between Olivia and Joanna, who had resigned and would finish work at the end of that week. There was obvious warmth between them and they seemed to 'take up where they had left off'.

Olivia said, "*we're kind of like very co-creative and like sort of like that old saying—a well-oiled machine. That we just slot in*". They immediately began planning their time together. Olivia had some things she wanted to do, and they decided together the order in which they could do them⁸¹ to maximise efficiency. Efficiency was one of the things Olivia craved, and which Joanna brought.

We went out to the car. Joanna had already positioned the passenger seat so that Olivia could easily get in. As we drove to the shops, bursts of laughter and exclamations of interest punctuated their conversation. We parked, and Joanna used her mobile phone to transfer money between two of Olivia's bank accounts. Then we went inside the shopping centre. Joanna fetched a trolley and Olivia pushed it; as Joanna passed me, she said quietly "*Now, watch this!*". The trolley acted like a sort of walking frame—only better. Leaning on it slightly, Olivia moved so rapidly that I sometimes had to run to catch up to them. For each item on the list, Joanna would read out brands and prices and Olivia would calculate—how many grams of carrots, for example, or which brand of toothpaste to buy. Olivia kept a running tally in her head, so that when they arrived at the check-out, she had kept to her budget and knew exactly how much money to get out of her purse. It was, as Joanna had hinted, a display of utter competence. Olivia's performance was masterful—but so was Joanna's. Joanna judged precisely the work she needed to do in order that Olivia's presentation of self was perfected. This judgement was displayed again when they stopped for coffee and a pie at a small café. The pie was served, and

⁸¹ Various sorts of shared planning was evident between Shirley and Winifred, Evelyn and Blanche, Anita and Sally, and Brian and Bill.

Joanna asked the waiter for some sauce. She watched as he went to get it. Seeing that he was returning with a small sealed plastic tub, which Olivia would find difficult to open, she got up and—unseen by Olivia, whose back was to the café counter—took the sauce and eased the lid up before handing it to Olivia. There was no fuss, no disabling ‘help’. It contrasted sharply with Stella’s presentation of Raphael’s toast.

Finally, my fieldnotes record what happened when we returned to Olivia’s:

Back at the house, two boxes of UHT organic milk have been delivered and are on the front door step. Joanna asks where she should put them, given the kitchen is a little cramped. She drags the boxes—they are very heavy—to the kitchen. They talk a little about organic milk and health. They’re talking as well about the fact that Olivia got her pension today and has spent “it all”. Olivia’s happy about it.

Joanna opens the milk boxes and hands Olivia the receipt. Joanna rearranges the shopping bags in the kitchen and starts to make a space for the milk boxes, while Olivia goes back to her desk in the loungeroom. Joanna now cuts down the boxes to make them fit in a space she has made, and says “A perfect fit!” Olivia gets up from her desk to come into the kitchen, saying “Let me have a look—I love perfection”.

She looks and says, “Wow—fucking perfect! Thank you my love”. They laugh and embrace. (Fieldnotes, observation)

What their photos revealed

When Olivia and Joanna took part in the photo-voice part of the study, they were aware of Joanna’s impending exit from support work. Olivia was both supportive of Joanna’s decision and devastated at the looming loss. Congruent with their observed and reported relationship, the photo-voice activity was shared; they discussed “*beforehand, you know, roughly what we were going to do*” (Olivia). Between them, Joanna and Olivia took 89 photographs. Their relationship and Joanna’s impending departure were the subjects.

Olivia took several images, experimenting with ways to show the grey pall she felt would fall over her life once Joanna left; Photo-voice image 3 is one of these.

Olivia described what she was trying to capture as *“that sort of space when you’re in no-man’s land but there’s shadows of what you love ...”*. She spoke of the aftermath of Joanna’s leaving with poignancy:

It was awful. It was like, um, it too, like I’d landed my mother-ship on a planet of fools, or something, because I just got, you know, I got funny people at funny times. I didn’t seem to be heard; it was just like really tricky.

There were other images she had wanted to create, but they remained imagined: *“We were going to do it on the last day, and then I didn’t realise how bad I was going to feel”*.



Photo-voice image 3. “That’s how I felt when Joanna left”

As well as depicting her sadness, Olivia’s images showed things she and Joanna shared, and she had photographed a collage she’d made, depicting their common cultural bonds and love of animals. Looking at this image, Joanna said, *“Oh isn’t that interesting. She’s so clever”*, and described how she *“look[ed] at*

Olivia—what she does for me! And she reminds me of home". Both women had taken photographs of Olivia and Joanna's dogs, and of walking the dogs together. Photo-voice image 4, in particular, showed this connection; Olivia described it as symbolising the freedom that came with Joanna's presence and their shared love for dogs. It was a reciprocal joy.



Photo-voice image 4. "Oh, that's wonderful! That's Olivia, isn't it? Walking stick and dog lead"

Olivia had taken a photograph of the garden. When Joanna and I looked at it, she sat back, almost sighing, and said, *"Oh, Olivia"*. She reflected on her work, saying *"[The clients] brought a completely different concept to my life"*. *"I just, I just clicked with them—you know? Common interests, fun, um ... each one of them have, like with the Italian lady, it's gardening. Olivia it's dogs. Evelyn it's intelligence, and generally animals and ... you know"*. This pleasure was evident too when they looked at the portraits they had taken. Looking at one she had taken of Olivia, Joanna's pleasure was evident when she said what a wonderful face Olivia had: *"When she smiles—and it's so easy to get her to smile"*. She continued, saying that

her delight was about *“what she does for me”*.

Olivia had commented on things she thought work did for Joanna. Work was *“satisfying [Joanna’s] need to be in the world with this ability to contribute to others”*. Joanna gained the *“sense of competence”* and the *“joy of doing things well”*. As her delight at Joanna’s solution for storing the organic milk showed, order was part of the self that Olivia wanted to present: *“When I moved in, it was like so precise. Yeah, you know, I love that. Because my cupboards inside—I love them to be tidy”*. Joanna understood that need and worked to satisfy it. Thus, Olivia photographed a neatly stacked cupboard (Photo-voice image 5), and the perfectly housed organic milk



Photo-voice image 5. “...it also really shows her, um, what’s the word, ingenuity, and, and, and starts with an ‘m’—not methodology, but something like that. Um, order—it fulfils my need for order when I’m looking at that”

On photo-voice

The photo-voice data from Olivia and Joanna and from Evelyn and Blanche added information about their different ways of interacting. For the former, Olivia's description of their relationship as being infused with a "*feeling of mutuality, of working like a team [...] mutual respect and appreciation*" rang true. Their pictures showed shared pleasures, and delight in one another. There was no sense of the (subordinate) helper or power struggle that was sometimes apparent in the images Evelyn and Blanche made, and their remarks about them. Joanna and Olivia did have more in common—they had a shared cultural history, and were both well-educated. Joanna saw her role as an opportunity to be competent; doing the best possible job meant having the client's complete needs met. And she was alert to that particular client: at work, she was present and fluid, "*like mercury*". She had little interest in being kind or being thanked; doing a good job was about the client's experience and sustaining their performance. Evelyn and Blanche, on the other hand, each displayed concerns about how they might be perceived and had a somewhat competitive relationship in which delight and working for one another's presentation of self were sporadic.

Summary: Enabling, "feel good" interactions

Becoming people to each other did not just happen. Workers and clients needed to pay attention, be reflexive and do emotion work. Emotion work prepared them for the interaction, and continued in their attention to one another and their reflectivity. There was "*no such thing as yeuch*", no pity, 'poor me', or victimhood. Becoming and being people to each other relied on workers *and* clients understanding that, as Anita had put it, "*we're all human; it all happens to us*". Indeed, the manifestations of "*no such thing as yeuch*" seemed to be the deepest expression of their shared humanity.

Becoming people to each other was a virtuous circle. When the assumption of shared human-ness was made and accompanied by attention, emotion work and reflexivity, each person was able to present their competent self. Workers could demonstrate their instrumental skills, completing tasks in ways that matched the clients' or residents' wishes, and that tallied with their own need to see themselves as competent, compassionate and ethical. At the same time, clients were supported to present their own competent self: they were 'tidy' for public performances, and had the opportunity to use other skills (e.g., Raphael's counselling, or Bill's teaching) that might have remained dormant. This was a co-creative process. Co-creation reflected the interdependent nature of the support relationship (Featherstone, 2010; O'Dowd, 2012; F. Williams, 2001). Their individual presentation relied on the other. Sally put this simply, saying:

I think they get a lot of satisfaction. [...] I think they all enjoy doing what they're doing, so it must be the caring part. It must be the making the client—[...] Ah, they just make us satisfied and happy—yeah. And I think it makes them feel nice.

But not everyone felt nice or was able to manage their emotions enough to "sustain the outward countenance" that might create the "proper state of mind" in the other (Hochschild, 2003b, p. 7). Goffman proposed that the maintenance of face in interaction relied on participants to be "disinclined to witness the defacement of others" (Goffman, 1967, p. 10). Some people in the study seemed not to display this disinclination. Were these participants driven to present competent selves by distinguishing themselves from others who were 'damaged' and leaky (in the case of Tilda, or Tash), or who lacked cultural or class status (in the case of Norah, Sally and Winifred's "girls" or Evelyn's word book)? In these moments, the support partners were not 'people to each other', and interactions were disabling in small or large ways to both people.

Enabling, disabling and the self—a preliminary model

Benjamin's 'sovereign other'

The understanding that "*we're all human; it all happens to us*" echoes Jessica Benjamin's (1988) description of the moment when a child understands that her mother is a "sovereign other" — a being with the same needs, responses and value as themselves. Without this understanding, an unequal relationship may develop in which one person (child-like) demands that their needs and desires are satisfied by the (m)other. This describes a way in which some clients and support workers interacted. It is also reminiscent of toxic forms of care and support in which clients' lives are shaped to suit convenience or budgets, and needs beyond the instrumental basics are ignored. These sorts of oppressive regimes have in part driven disabled people's abhorrence for the word 'care'.

In Benjamin's discussion, seeing the other as the self enables the other to be a model: "A person comes to feel that "I am the doer who does, I am the author of my acts," by being with another person who recognizes her acts, her feelings, her intentions, her existence, her independence" (Benjamin, 1988, p. 21). Thus, the self is strengthened through relationships and socialisation (as Goffman (1967) also argues). Recognition—or presentation of self—is, therefore, "reflexive; it includes not only the other's confirming response, but also how we find ourselves in that response" (Benjamin, 1988, p. 21)

What happens, then, when there is no confirming response—when support partner, organisation or society constructs one as incapable or as having feelings or needs that can remain unmet? The absence of a confirming response is a negation. It constructs the person who has been demeaned or disabled as having "nothing real to give" (Benjamin, 1988, p. 35). There are costs for all those involved in such negation, since "if I completely negate the other, he does not exist; and if he does not survive, he is *not there* to recognize me" (Benjamin, 1988, p. 38). The dominator becomes amorphous, isolated, alienated: there is

nothing fighting back, nothing describing boundaries around the self. Winning the "battle for omnipotence" results in "emptiness [and] isolation" (Benjamin, 1988, p. 35). Tilda's battles with Kostas and Beryl, the tension between Blanche and Olivia, Evelyn's word book, or the pity and sarcasm between Stella and Raphael were all interactions that denied one or other (and therefore both) full, sovereign status. Each would "feel bad because he had relied upon the encounter to support an image of self to which he has become emotionally attached and which he now finds threatened" (Goffman, 1967, p. 8). The person will "falter, collapse and crumble" (p. 8). Instead of co-creation, there is mutual disabling and alienation.⁸² Conversely, becoming people—sovereign others—to each other is a mutual project of the self.

Conclusions

It's not about mopping the fevered brow, or you know, going to the old lady ... there's something else that's a fine quality [...] almost be, like you're ... —ah, the authenticity! That's what's missing! That's what's missing. You know, it's become known in society as caring when "Oh, she really cares; she does all this stuff for people", but is that person really being authentic? (Olivia)

Workers and clients were working to sustain the presentation of competent and congruent selves, in the face of both demeaning and disabling external constructions, and potentially risky interpersonal interactions.

In enabling "feel good" interactions, both clients and workers gained from the relationship, making it possible for each to present a competent, congruent—and, as Olivia has it, an authentic self. There was ease and engagement between worker and client. Each did things in the interaction that enabled one another and assisted in the presentation of desired selves. Satisfaction came from the

⁸² Some sought (and possibly gained) the necessary "face" elsewhere. I surmise that support workers, administrators and other organisation staff who batted away complaints were saving that face that was embedded in the social world of facility or organisation staff. They were maintaining face amongst those to whom they were strongly tied (Granovetter, 1973).

competence, the congruent self each was able to present.

In disabling, “feel bad” interactions, on the other hand, the relationship actively disempowered those involved—at least for the duration of the interaction—such that the self presented by both was as incompetent or incongruous. Disabling relationships were faintly or overtly combative, the work was performed somewhat regardless of the actual needs of the client, and the players were competitors not collaborators. Workers’ satisfaction was in getting everything done, not in meeting a need or in doing a good job. Clients often wanted these workers to leave as soon as possible, reduced the tasks that needed doing, or rejected workers altogether.

These differences were discernible in the conversations I had with all workers and clients. It was apparent in the portfolios of photographs two dyads prepared, and in observations of the dyads together.

Building on Benjamin’s (1988) notion of the recognition of the other as a ‘sovereign’ being, I re-visited the literature to see how others had understood this mutual project. I reread Shakespeare (2000), writers on the ethic of care (including Featherstone, 2010; Fine, 2007a; Held, 2002; Hughes et al., 2005; Sevenhuijsen, 2000; Tronto, 1995; F. Williams, 2001), and thence the work of Nancy Fraser (1995, 1998, 2000, 2001) and, especially, Axel Honneth (1996, 1997). Honneth’s recognition theory presented a theoretical framework for linking meaning, practice, self, other and presentation of self. The role of recognition theory in understanding the intersection of meaning and practice in aged care and disability support is the subject of the next, final, chapter.

Chapter 8.

Discussion: Becoming people to each other

A person comes to feel that "I am the doer who does, I am the author of my acts," by being with another person who recognizes her acts, her feelings, her intentions, her existence, her independence ... (Benjamin, 1988, p. 21)

*And so I had, like, an opening. And you know, as soon as you make a connection, there, there, any walls that they've put up to you as a health care provider, come tumbling down. And, you know, even the thing that they will, they hate doing—whatever it is—you can somehow get them around, because you, because you, you've opened it up a little bit. You've taken a barrier down; **you've become people to each other.** (Jai)*

Introduction

This is a study of how practice and meanings of care intersect in the delivery of support to people with disabilities and the frail aged. I used ethnographic methods to gather data from 29 participants as well as to present a picture of the political and societal contexts in which these 29 people perform. At the end of the 18 months of formal data gathering, I had more than 100 transcripts of interviews, fieldnotes from observations and casual conversations (see Table 3.3). As well, there were reflective diary notes covering the multiple encounters, and the directly or peripherally-related events where reading and thinking sparked shifts in my understanding. There remains much that I did not see or hear; I was, after all, the 'researcher near' (Mannay, 2010)—neither a true insider nor a detached outsider. The iterative thematic analysis sometimes felt like trying to find my way with my senses all shut down. But some incidents

sparked a shift in my understanding; they were the “That’s funny” moments where something either did not make sense or was unexpected. The first of these came as I drove to an early interview with Raphael.

Recognition—the participants and I

In my preparations for recruiting and then for interviews and observations, I paid attention to my performance. Did my photograph on the recruitment fliers present the right mix of serious and friendly? What should I wear to meetings and observations? What should I tell them, and which words should I use?

Given that I wanted participants to be candid with me, how much and what should I reveal about myself? But driving to Raphael’s one day, I became aware that there was more to my performance than these surface elements

(Hochschild, 2003b): I noticed that I was thinking—“*I wonder if Raphael has fallen in love with me yet?*”. The idea of love came as a shock. I tried to make sense of it: it seemed a sort of love between participants and me was necessary if trust were to develop (Ezzy, 2010). This was the love of interest, of caring about one another; a sort of platonic infatuation, perhaps. I gave participants my full attention. They were, after all, essential. I loved and recognised their expertise—on their own lives and on practices and meanings of care and support.

A second sort of performance became apparent during an observation. When I first met Evelyn, we talked about how the books were arranged on her bookshelves and about the meanings of words, or the best word for a particular situation. She used the phrase “*more frequently*” and then immediately said, “*Is that tautology—I think it is*”. Evelyn was animated and enthusiastic, enjoying the banter between us, and displaying her large vocabulary as well as her capacity to use it skilfully. She was performing for me, showing me an important part of her identity. Then I started to notice that all other participants too were performing and, like Evelyn, seeking common ground. Raphael and Brian reminded me of their wit and skills with gaining the trust of others. Nicko told

me about his historical high-level knowledge of timber and timber-craft. Bill and Leonie displayed their managerial and ethical depth. Tilda blossomed when I asked her about instrumental skills and knowledge. Erica made several remarks that invited me to acknowledge our shared experiences and opinions. In the same way that I shaped my descriptions of myself and the project to the different audiences, wanting to connect, participants were presenting selves that were competent and congruent, choosing carefully the things that were their own strong points and with which, as they got to know me better, they saw that I would engage. And the interviews and observations showed that they were also performing for one another. In a post-observation interview, for example, Evelyn checked my impression of her and Blanche's manner with one another: "*Amicable, did you think? Well I did anyway*". The data I gathered—in interviews, observations and through photo-voice—showed that I was simply another audience for what was a constant presentation.

All performances, presentations of self, pointed towards an overarching way to understand what I had seen and heard: we were all, workers, clients and researcher, seeking and enabling (or disabling) recognition.

Recognition and misrecognition

Axel Honneth (1996, 1997, 2001, 2003) proposed that recognition is required for a decent society, one "whose institutional practices and measures respect all the subjects affected in the sense that each can see him- or herself recognized as a member of the human community" (1997, p. 18). Recognition, he argues, may occur between two individuals (mother and child, lovers, friends) and create self-confidence. He labelled this primary level of recognition 'love' (and see Roberts, 2010). In love, the recognition is of one's needs and desires as being uniquely valuable to another person; there is emotional, individually-focused care (Honneth, 1997, p. 32), and it may be asymmetrical.

Beyond this intimate 'love' recognition, Honneth adds two further conceptualisations of recognition. The first is recognition at a community (and legal) level — 'rights'. Here, the self and others are assumed to have the same moral accountability and be deserving of "universal equal treatment" (Honneth, 1997, p. 30). This creates self-respect. 'Solidarity' is the third level of recognition. Here, one's capabilities are recognised as being "of constitutive value to a concrete community" (p. 30); each person is seen as contributing something of value. Self-esteem is the result. These three levels of recognition shape both the interaction and the self. Recognition at the 'love' level creates self-confidence; at the 'rights' level, self-respect; and at the 'solidarity' level, self-esteem.

Like Goffman (1967) and Benjamin (1988), Honneth argues for the interactive creation of self. Where Goffman talks about self and face, Honneth writes:

That human subjects are at all vulnerable in their conduct with one another follows from the fact that they can construct and maintain a positive self-relation (*Selbstbeziehung*) only with the help of agreeing or affirmative reactions on the part of other subjects. (1997, p. 24) (*italics in original*)

All three writers link how the interaction proceeds with how the actors regard both themselves and the other. And just as Goffman (1967) argues for interaction as the site where face is established, sustained or damaged, Honneth writes that recognition signals the extent to which individuals comply with social norms. Interactions are mechanisms through which we may be encouraged "to acquire desirable virtues" (1997, p. 16), as well as self-relation: "the consciousness or feeling that a person has of him- or herself with regards to the capabilities and rights this person enjoys" (Honneth 1997, p. 25).

Recognition can be absent, damaged, or removed. Misrecognition occurs when some "aspect of recognition is being withheld or denied" (Honneth, 1997, p. 23). At the person to person level, the ways in which recognition fails are evident in

physical and emotional abuse, in rape, torture and murder. These injuries signal that one's physical and emotional needs are not valued by another; it is obvious that (at the very least) self-confidence is damaged by such failures of recognition. The presumption, at the second, rights, level, that one's judgement is sound and valuable is damaged by constant supervision, for example; institutionalisation or surveillance imply mistrust in one's judgement. Self-respect is at risk. At the level of solidarity, disrespect or humiliation and stigmatisation or being rendered invisible all "harm the feeling of being socially significant" (Honneth, 1997, p. 27). Nancy Fraser adds that misrecognition is the depreciation of group-specific cultural identity by the dominant culture,⁸³ with resulting damage to individual members' sense of self (2001, p. 23). Such misrecognition "constitutes a form of institutionalized subordination—and thus, a serious violation of justice" (2001, p. 26). In misrecognition, one's status is lowered and self-relation, self-confidence, self-worth or self-esteem are damaged.

Recognition and misrecognition were evident in the data. The next section links the performances and presentations of self of workers and clients in the study with recognition and misrecognition. Then, I consider what forces are operating on participants and how those forces shaped interactions.

The enabling to disabling continuum as recognition to misrecognition

In Chapter 7, I proposed that interactions between workers and clients could be placed at points on a continuum. At one end were interactions that were disabling. Neither client nor worker could present their desired self. Their presentations were disabled by resistance, by unequal relationships in which one was positioned by the other as (an) invalid, or treated as a servant or child.

⁸³ Or, as Honneth (2003, p. 141) puts it, the "value standard", one that is bound up with hegemonic masculinity and its trappings (and see Fisher, 2008).

At the continuum's other end were enabling interactions. Here, worker and client engaged in co-creation of one another's desired self. Dotted between these poles, and sometimes oscillating along the continuum, were the majority of interactions reported or observed.

Honneth's recognition model provides a rich way of interpreting these positions as well as offering ways to increase enabling encounters. I consider first the features of disabling relationships where misrecognition was evident, and workers and/or clients experienced—and perpetrated—moral injuries.

Disabling interactions: Moral injuries and misrecognition

Disabling interactions involved “the disrespect of personal integrity that transforms an action or utterance into a moral injury” (Honneth, 1997, p. 23). Injuries to solidarity, rights and love are evidence of misrecognition.

Injuries to solidarity

Solidarity is that form of recognition in which one is seen to be contributing to a common project. Aged care and disability support workers are engaged in work that is necessary: supporting people to lead ordinary lives. Their contribution to this larger social project should result in recognition at the solidarity level. Yet workers experience injuries to solidarity in their still low wages, in calls to remove penalty rates,⁸⁴ and in funding pressures that precipitate providers to, for example, limit workers' daily claims on travel between community clients. Similarly, clients have a much higher likelihood of poverty than Australians as a whole (Australian Council of Social Service, 2014), and are experiencing increasing strictures on access to supports (Buckmaster, 2015), effectively reducing their opportunities to participate in the

⁸⁴ Penalty rates are payments made for work performed outside standard business hours, for example on weekends and public holidays.

larger project. The moral injuries of invisibility and stigmatisation signal that one's "capabilities do not enjoy any recognition" (Honneth, 1997, p. 27). They cast "some categories of social actors as normative and others as deficient or inferior" (Fraser, 2001, p. 25).

Stigmatising public discourse

Long before the idea of recognition had lodged itself in my thinking, the people I had been talking with had pointed to it, and the media review had made clear the stigmatised position both workers and clients occupy.

The review, reported in Chapter 4, found that workers and clients were portrayed in essentialised, homogenous ways—the workers as alternatively capable, inadequately trained, greedy or cruel, the people with disabilities as passive and pitiable victims of individual, institutional and system-level vagaries. Policy statements framed the low- or un-waged as undeserving 'leaners', who took advantage of the (deserving) 'lifters'. This was consistent with the literature on how people with disabilities and older people appear in media (Chapter 2). Further, these stereotypes rendered real lives invisible, as did the dearth of research reporting the experiences (and voices) of care and support workers. The social identities constructed and sustained in public discourse (Haller & Ralph, 2001; Rozanova et al., 2006; Shakespeare, 1997; Sontag, 1990) were damaging to workers' and clients' group identities, inflicting moral injury, or misrecognition (Fraser, 2001).

Towards the end of this study, a new round of stigmatising media articles appeared, arguing that the Disability Support Pension was an "unsustainable" "burden" (Crowe, 2015, p. 1). The front page article was littered with the language of risk: "outstrip inflation", "threat", "swollen", "vigilance" required, "forcing a greater contribution from those who stay in work", "the load that workers have to carry", and that it was too easy for people to "opt out" of

responsibility (Crowe, 2015, p. 1). The newspaper's editorial cemented ideas of people with disabilities as failing citizens by ascribing part of the 'problem' to Australians being "less inclined than they were generations ago to face and overcome hardships and stresses" (Editorial, 2015). This reiteration of the 'lifters and leaners' discourse confirmed the stigmatised position and lack of solidarity experienced by clients and workers.

Stigmatising private discourse

Individual-level instances of stigmatisation and marginalisation were also reported in the study. Raphael's suspicion that a worker did not "*want to spend too much time with me*", Tilda and Shirley's confessions of feeling awkward around some people with disabilities, and Tilda's willingness to shame residents who expressed their sexuality were among the examples of stigmatising. Bill's experiences of "*being lied to*" and "*taken for a fool*", positioned him as not valued, and were echoed in Raphael's "*What do I look like, I'm stupid?*" remark about workers who did a poor job. The several clients who resisted administrators' obfuscating responses to complaints were, Olivia thought, supposed to "*feel bad*". Her own failure to perform according to a stigmatised, 'vulnerable' script created difficulties for her (and see Hollomotz, 2006, 2014). Finally, the unstated requirement that clients should be grateful (and many worked hard on this) indicated that the supports that enable an ordinary life were not regarded as a right. Two clients' requests to providers for changes or additions to support provision were met with allusions to a "*lolly jar*" and "*candy store*". These metaphors positioned support as a luxury—a kind of cherry on the top. In such discourses, the ordinary life and the possibility of experiencing solidarity, of being considered a contributor to a larger project, remained out of reach.

Injuries to rights

Self-respect is injured when the moral accountability or judgment of individuals is disregarded or devalued.

Trust

In their function as the 'eyes and ears' of community- and—to a lesser extent—residential providers, workers are presumed to have sufficient moral accountability or judgment to be present with clients and residents in situations where risks of abuse, theft, and exploitation exist. Yet, their judgement was not trusted when they made requests for changes to support provision for clients or residents. Workers' pleas for facilities not to work to a (possibly false-) economy of changing incontinence pads only when they were completely sodden, for an additional short visit to community clients to change incontinence pads more frequently than the 12-hourly regimes in place, or for cleaning of dentures to be included in workers' morning routine, for example, were greeted either with unfulfilled promises for action, or with a blanket refusal. More personally destructive was the assault on the worker's moral authority by the care-less handling of the accusation of theft made against her. Olivia commented on the destructiveness of such misrecognition, arguing that *"it eats people's intentions"*, and Bill concurred.

Bill and Raphael identified another sort of stigmatisation: organisations' failure to appropriately manage workers who were dishonest (including lazy) or who did extras, and to adequately prepare workers for clients new to them. These failures were, in Bill's words, forms of *"betrayal"* and *"subversion"* that devalued *"the whole care fraternity"*.

Supervision and surveillance

Supervision and surveillance—and their close companion, protection—can deny agency and recognition and imply inadequacy or incapability in the watched. Honneth (1997) foresaw that a struggle between risk and recognition

could arise when choices had to be made between the sovereign other's right to autonomy and their simultaneous need to avoid injury or violation to recognition at the person to person level. Similarly, Hollomotz (2014) argued that the responsibilities of support (or care) workers may conflict with the act of recognition of enabling choice for clients (and see Chapter 2). People with disabilities have historically experienced protection-driven restrictions on choice and autonomy (Hollomotz, 2014), but more 'modern' responses like normalisation and personal plans continue to set boundaries and norms (e.g., see Hollomotz, 2014; Kim, 2011; Rogers, 2010). Indeed, the demands of normalisation and personal plans can encourage a state of almost permanent training for people with disabilities. They have been enhanced by work-focused measures of human value (see Houston, 2010, on *Homo economicus*), and newly fashionable promotion of 'active ageing' and 'successful ageing' impose similar pressures (Holstein & Minkler, 2003; Lloyd et al., 2013; Moulaert & Biggs, 2013; Ranzijn, 2010). Evelyn commented on her ambivalence about the work she needed to do in order to manage a consumer-directed aged care package. Tash and Vic spoke of their roles in ensuring residents' busy-ness, and Erica and Gerry made several self-critical comments about their performance on various tasks set out in their own personal plans. It was not clear why they were expected to perform these tasks nor whose yardstick was being employed.

Workers experienced supervision and surveillance, and providers' adoption of smart-phone technologies will enable greater rostering efficiency, as well as greater oversight. Supervision and surveillance (of both workers and clients) also manifested in the communication books, case notes and reporting, assessment instruments, and in pressure on clients to take medication, and to fit into the schedules of organisations. Clients were subjected by these means to "literal and figurative institutions" (Kelly, 2011, p. 564). This was exacerbated by the frequently commented on fact (e.g., "*They don't ask people*" (Cornelia),

and “*Nothing’s explained*” (Norah)) that clients were often not told about changes to workers, or to rostered service times and were not included in other decisions that affected them directly.

Judgment

Clients’ moral accountability or judgment was called into question by the various forms of protection operating. Erica was being protected from risky others in the ban on hugging. It was assumed that she could not be responsible for her sexual or social behaviour (see Block, 2000). She was thus positioned between the moral injuries of having her needs and desires stymied, and of potential abuse. The personal plan, in which the ban was set out, was premised on ideas of choice and self-determination (Jenny Morris, 1993; Schelly, 2008), yet risk to safety discourses disabled the sexual and intimate life of Erica, as it does for many other clients and residents—especially those with cognitive difficulties. They are positioned as asexual, innocent and/or lacking judgment (Block, 2000; H. Brown, 1994; Di Giulio, 2003; Shildrick, 2007; Shuttleworth et al., 2010; Tarzia, Fetherstonhaugh, & Bauer, 2012). Hamilton reported that expressions of sexuality or closeness were often “treated with either amusement or anxiety” by disability support staff (2002, p. 3 of 17). Tilda’s response to her own anxiety was the humiliation of residents who masturbated and her remarks about the woman who was rumoured to have been a brothel-keeper.

Tilda was not alone; other workers’ physically disabling actions also threatened clients’ self-respect. Raphael was frustrated when Stella put his breakfast plate precariously on his knee, and when Tanya stored the nuts he had been looking forward to eating in a high cupboard. These seemed to be examples of misrecognition: disabling by thoughtlessness. Stella and Tanya appeared to have forgotten Raphael’s limitations. Being positioned—whether deliberately or not—as incapable angered all clients.

Institutionalisation

Often, organisations and workers imposed ways of living on clients or residents. In facilities, residents' physical needs shape some aspects of the arrangement of rooms, and the same can be true in houses and flats. As well, the timetabling of workers' and clients' interactions left some feeling like commodities. Several workers described the time demands while making the same rapid chopping gesture with their hands. Time pressures had Sally waiting in her "*jammies*" till late in the morning, and inclined Winifred, Norah, and others to refuse the rushed and unpleasant showers that resulted. Other forms of adjustment included Cornelia's awareness of the need to be alert to her every habit: whether towels were to be folded or rolled, and how mugs were stored. Tash was angry that residents were not allowed to sticky-tape or BluTak posters to the walls of their rooms, despite Harvest being—for most—their only adult home. Erica felt the presence of her house-mates made it impossible to invite friends for sleep-overs. And Laurence commented that some workers treated his place as "*a workplace and not a house*", arranging his possessions in ways that simplified their work but made his house impersonal.

All these changes (echoes of Goffman's institutions, 1961b) implied that clients' own judgments were somehow incorrect or ill-advised, and that the provider's needs would take precedence. Making non-essential changes repressed clients' and residents' identity and diminished recognition. Those changes that were necessary were sometimes not the result of an informed or democratic negotiation.

In these examples, both clients' and workers' judgement was being ignored and their self-respect and recognition of their rights undermined.

Injuries to love

Time and physical pressures institutionalised clients and infringed on workers'

moral authority. Injuries to physical wellbeing, and dismissal or lack of consideration of the emotional demands of support work, undermined recognition at the person-to-person level: individuals' confidence that their unique needs mattered to others.

The need for intimacy

The hugging ban imposed on Erica was an instance where needs and welfare were in conflict, but there were other less ambiguous examples of moral injury at the 'love' level. Vic described the sham marriage of two people with disability, concocted by their parents and case managers but not understood as fake by the couple. Workers' love and care for clients went unacknowledged in organisations' sometimes brutal reporting of clients' deaths. That Anita was left uninformed about Sally's death is a particularly stark signal of misrecognition. Indeed, organisations' discouraging of friend-like relationships in the support interaction is itself an act of misrecognition.

Tilda's efforts to repress residents' sexuality actively undermined their needs being met. At this 'love' level, Tilda was unable to offer clients or residents recognition. As well as her humiliation of the sexually active men in the facility, failure was evident in her mocking Beryl, her adding a witness to the already ashamed explosively incontinent woman, and her bossiness and bickering with Kostas. And she paid the price: clients and residents rarely gave her the signals she needed for self-confidence, self-respect and self-esteem.

Inattention

Paying attention shows the other that their needs and desires are uniquely important. While Goffman's notion of civil inattention (1963a; Longmore, 1985) explained some lapses in workers' knowledge of clients' lives and actions, there were several observed and reported examples of workers not listening, and of appearing not to understand, or make an effort to do so. Sharon, Edwina, Tilda,

and—to a lesser extent—Stella, had all made do with limited or no understanding of what clients or residents were saying. Gerry was not, to Sharon, sufficiently valued for her to care to find out what he did at work, though he had explained it. The failure of workers to try and understand what people were saying is disabling.

At Cliveden, Norah gave several example of workers (at various levels in the hierarchy) failing to respond to residents' needs. Some of these were very pressing, as her experience of being left on the floor of her room with a dislocated elbow for "*a couple of hours*" showed. Other participants reported more subtle forms of inattention. Olivia felt that workers often had several things other than support work occupying their attention, and Evelyn forgave Blanche's occasional "*lapses*", saying that she had "*a lot on her mind*". Some workers were unable to leave personal concerns at home.

The importance of being present, of mindful support, was flagged by Olivia. It was a characteristic of her own experiences with Joanna, but missing from her contact with Blanche. Laurence, too, missed such presence in the support he had received that treated him like "*a robot*", and Jai commented on his own resistance to performing robotically at work. If one is unable to present the desired self, and have that presentation acknowledged (and recognised), then interactions are "feel bad".

Repair and rectification of misrecognition

The support encounter is an endeavour that both worker and client may contribute to or damage. In the absence of mutual recognition, clients' presentation of self is thwarted. The disabling they experience drives resistance, refusal of support, or other responses that make the work harder. The result is that the worker is unable to complete the requisite tasks. While some may be glad to have an 'early minute', they may also find that their own presentation of

self—as a supporting, enabling, competent worker—has been disabled. A cycle of failed presentation ensues, leaving both parties unable to gain the recognition they desire. Nonetheless, misrecognition was not, necessarily, a permanent state; several observed and reported interactions showed the important role of emotion work, and of changes in external factors, in recovering recognition.

Interactions that fell somewhere between disabling and enabling, or that seemed to oscillate along that continuum, shifted towards enabling and recognition when one or other did emotion work, or when external factors intervened.

When Stella, having been careful not to touch Raphael, crouched down, looked him in the eye and put her hand on his knee, she seemed to be making an appeal for *détente*. Their ‘old married couple’ routine had been briefly amusing, but it displayed an inequality—in power, in cultural capital and in gender roles. Her gesture, and his response, appeared to restore recognition. Similarly, Norah’s capacity to value the staff at Cliveden changed after her family phone call; it performed the function of re-instating Norah’s own competence (as ‘mother’, grandmother, a respected, included, and loved person). Having thus experienced mutual recognition, her self-confidence, self-respect and self-esteem were re-established, and she was more able to withstand the moral injuries of facility life. Emotion work was at the heart of these restorations. It was present, too, in Anita’s reflexive realisation, and subsequent change in practice, that workers could not “*make life more enjoyable—we can just make it more comfortable*”, in Olivia’s efforts to “*see the value*” in a new worker, her “*work for those two weeks*”, and in Evelyn’s efforts with Ann-Marie.

Enabling interactions: Emotion work and recognition

Enabling interactions involved signals of “the mutual respect for both the particularity and the equality of all other persons” (Honneth, 1997, p. 18).

Solidarity

Feeling able to make a valued contribution was important for all participants. Tilda did this when she showed me her instrumental knowledge, giving clear descriptions of her 'tools of the trade' and their uses. She felt competent. She also gained a sense of efficacy from aligning herself with her employers and her colleagues (to the extent that she did). These were claims to solidarity—to being recognised as having something to contribute to the project of aged care. Brian spoke of a more immediate sign of recognition at this level, when he validated Delia's domestic work. He understood her reports of cleaning, of setting the fire, of managing money as central to her identity, contributions to the project of family and marriage (roles she spoke to me about with pride).

Rights

Demonstrating recognition of one another's judgment and moral authority was evident in several of the dyads, as well as in reported interactions. Joanna asked for Olivia's advice about her pets, and Brendan and others turned to Raphael for advice about their personal lives. Brian took care not to undermine Delia's experiences of solidarity; he also expressed overt admiration for Bill's honesty and affirmed Bill's capacity and judgement by asking for help with learning some of the difficult material in his course. And Bill, in return, made his respect for Brian's capacity and judgement very clear; they each wanted the other to succeed. Such mutual trust and valuing were also evident between Anita and Sally, Leonie and Nicko, and Shirley and Winifred. In each case they were demonstrating shared endeavour and respect.

Love

When Anita sang "Amazing Grace", and when Vic sat with the weeping Ellie (Chapter 5), both were 'flying blind'. They said clearly that they had no idea what to do, and their voices in the retelling had an edge of panic. Yet in both

cases, they seemed to do exactly what was needed. Anita was present with the dying woman, singing and holding her. And Vic empathised with Ellie—he knew what she was feeling. They recognised the other and responded to their unique and pressing needs. There was no rule or policy for these events. Vic and Anita had been faced with unexpected and emotionally intense situations for which they were not trained and received little guidance. Perhaps this lack was understood by them as signalling trust; they certainly felt sufficient self-confidence to rely on themselves to interact appropriately—and with love.

The same love was evident in Brendan's work with Raphael. Brendan understood that he had a role in presenting Raphael's chosen self: he was working on this when he asked Raphael how his clothing for the day made him feel. Raphael's unique needs were given Brendan's focused attention. These two men were confidants, each seeking the advice and support of the other.

Love brought ease to these interactions, and to Sally and Anita, to Olivia and Joanna, and to Evelyn and Blanche. It made Bill and Brian speak with deep admiration for one another (and, indeed, consider one another father and son). Winifred and Shirley were relaxed and engaged in one another's lives, as were Leonie and Nicko. Love gave Laurence and Edwina a closeness that they described as sibling-like. In this ease, each person was enabled to present self as they wanted.

Recognition: Summary

There were numerous versions of the successful service encounter in this study, and they were connected by attention, by respect, and by mutuality.

'Successful' service encounters relied on the emotion work each person performed. Each person worked to "sustain the outward countenance that produces the proper state of mind in others" (Hochschild, 2003b, p. 7) by paying attention to their unique needs and desires, by demonstrating faith in

their judgments, and by enabling each to contribute. They could *“become people to each other”* (Jai).

In these circumstances, clients accepted the presence and acts of support and in turn enabled workers to assist in their presentation of self. For workers, presentation of self was also thus enabled: the worker needed to be able to work, to feel their work was effective, efficient, valuable, was making a difference, and that they brought something particular to it. They could only do this when clients allowed them to perform, and clients would only do so when the worker had demonstrated that their needs were uniquely important and that their judgment and authority were intact. Sally encapsulated the mutuality of the endeavour, saying *“they just make us satisfied and happy—yeah. And I think it makes them feel nice”*.

What enabled or impeded recognition?

The presence or absence of recognition was relatively easy to detect. The role of emotion work was clear. But why could Joanna respond reflexively to Olivia’s occasional brusqueness while Blanche resented it? Why were Olivia’s capacities admired by Joanna and mocked by Blanche? Why did Joanna refuse to drive her own car to distant clients and instead book the company vehicle, while most other workers in the study drove hundreds of kilometres, unable to immediately claim their travel allowance and instead waiting for an often-distant tax return? Why could Miriam, Lilla and Brian meet the rages of people with dementia with gentleness and fellow-feeling, while Tilda retaliated? Why did Tash adopt a blaming tone about a resident *“who broke my ankle”*, while Vic sought ways to enable James, comfort John, and express his fellow-feeling with Ellie? And why did some workers—rejecting the repeated moral injuries they experienced at the hands of organisations—leave support work, while others remained? It was apparent that there were structural as well as individual

forces shaping encounters, such that enabling or disabling of recognition resulted.

Organisations and policy

The role of the institutional forces of policy and media discourses in moral injury has been set out. Policy—and public discourse—had dramatic impacts on provider organisations. Subject to policy that devalues both clients and workers, organisations are forced to make do with less and experience greater and greater surveillance.⁸⁵ These pressures shape how organisations behave towards clients and workers.

Organisations imposed rules, established work practices, signalled trust or mistrust of workers and clients, set up surveillance, and could enable or disable connection and relationships, exercising control over whether workers were able to perform the self they desired. They affected clients through rostering and assessment decisions, and through the direct contact they sometimes made.

Social class

There were discernible social class differences between participants in the study (see footnote 63, p. 208). A number of clients drew attention to class in their comments: about workers' manners or ungrammatical speech, as well as about their sometimes chaotic-seeming lives. When some of the female clients who had been professionals in their earlier working lives called workers 'girls', they were alluding to class and status differences. Jai felt that his educational and cultural capitals set him apart from most other workers, while Raphael, aware of his own much greater education than most of those who worked with him, argued that "*smart*" had nothing to do with being a good support worker. The contrasts between workers, though, may be more straightforwardly viewed in

⁸⁵ I am not advocating that oversight and surveillance be removed.

terms of the impacts of life chances. A comparison of Tilda and Joanna is illustrative.

Life chances

Tilda, with her sincerity, her idealism, her deep pain at the losses she had experienced, her emotions in turmoil just below the surface, presented as a very different sort of worker from Joanna, though Joanna too had experienced losses and turmoil. Tilda slipped easily into self-justification and small (and large) acts of cruelty or power-play. For her, work was something to be got through as rapidly as possible. If the assigned tasks of a support visit could be completed in less than the allotted time, one could leave; the possibility that there was an important social dimension to her work was not mentioned. Indeed, it appeared that the demands and needs of recipients were a source of annoyance, pain or fear for her rather than something unique for her to recognise and respond to. She repeatedly showed that she and all the people she worked with (be they other care workers or people she supported) were in some sort of competition or tussle. She mocked them, wished them to be different, and rarely spoke of them in ways that were validating or enabling. She failed to protect them from shame or indignity.

At the other extreme was Joanna. Joanna's admiration for the people she supported was apparent in all her actions. Her aside to me about Olivia's shopping—*"Now watch this!"*—was an expression of delight. She spoke of clients with love and gratitude, and of the few times clients treated her as a servant with calm understanding that confidently resisted this attempted positioning. She expected to be taken seriously by management and told me she had been left residential aged care work because of the cruelty to residents she witnessed. When clients talked about her, they too spoke of love, as well as admiration, respect and authenticity, words that Bill and Raphael had also used to describe Brian and Brendan.

I speculate that very different life chances separated those workers who expressed humiliating and stigmatising views of clients and residents from the others. Tilda's story was awash with dashed hopes, things started and never completed, ways in which her desires had been thwarted; in short—loss and misrecognition. She was clearly quite intelligent; her word choice signalled good verbal capacity and she had been accepted into a university course that required high grades. Yet her life chances seemed to repeatedly militate against exercise of this capacity. She belonged to a close-knit and somewhat ostracised religious group. She had an impairment that had pushed her into a 'special school' as a child. In adolescence and adulthood, various addictions resulted in medical interventions. Her marriage had been troublesome. Although there were loving relationships with her children, her desire to pursue more education (a potential status shield; see Hochschild, 2003b) had been repeatedly stymied by her unsupportive and obstructionist husband, who had physical and emotional difficulties of his own. She and—to a lesser extent—Tash and Blanche had experienced overt gender-related diminutions of agency, being pulled into situations and places where their ambitions were thwarted, by husbands or partners whose own needs took priority. In addition, several of Tilda's close family members and friends had recently died—some in unpleasant circumstances. All these factors were coupled with work that was, as she saw it, a poor cousin to her long-cherished vocational ambition, and was poorly paid. She had done no job other than aged care in her more than 40 years of work. In short, her life chances had been strikingly poor. She took few of the opportunities care work offered for self-confidence, self-respect, and self-esteem.

Joanna, on the other hand, had chosen aged care by a rational process when self-preservation forced her out of a very demanding, highly paid corporate job. She was well educated and self-confident. She had experienced some significant

traumas, but had taken seriously the need for self-care and found effective supports. In aged care, she developed egalitarian relationships with clients and refused to be pushed into emotionally, physically or financially costly situations by her employers or clients. She was the only worker in the study to ensure she carried no travel costs by using the company car. She expected to be treated as a valuable employee and did not stay late or break W H S rules at work. In short, she had self-confidence, self-respect and self-esteem.

When I applied a life chances yardstick to workers in the study, it held true as a measure of their likelihood of having sound self-confidence, self-respect and self-esteem. Conversely, where life chances had been poor and there were continuing assaults on self-recognition, workers' interactions with and perspectives on clients were more infused with moral injuries and misrecognition on both sides. There was also evidence that one's present life chances mattered. Anita, for example, had experienced some injuries and moral insults but she had the resources of a very supportive husband and a capacity for reflexivity that helped her surmount several challenges and to rescue interactions that had seemed destined for failure, and instead made them 'sing'.

Gender

Women, as members of a societally subordinate group, are likely to experience a kind of everyday misrecognition in 'ordinary life' (Fraser, 1995). Yet I speculate that in aged care and disability support, their essentialised group identity as caring reduces the possibility of misrecognition. Women may be protected by their fit within this constructed identity, though it also traps them in unhelpful performances. Olivia had a name for a game she said some female workers were playing: "*Aren't I stupid*". She argued that this gendered construction excused performances of helplessness and lack of creativity (a failing Joanna did not have). Another unhelpful performance was the outward acceptance of the sorrows and emotions of caring as natural. Grief can thus be

seen as just part of the job, relieving organisations of the need to actively provide adequate supports.⁸⁶ Taking for granted the idea that women are used to managing and absorbing such feelings means that the real costs of grief are poorly acknowledged and solidarity and love are not offered. Another gendered performance was Stella's wife-like role in her interactions with Raphael. He reported quite different ways of interacting with Brendan and Xavier.

Men in the female dominated care and support workforce may, on the other hand, be experiencing misrecognition. This may partly explain Brian's very overt performance of hegemonic masculinity (Connell & Messerschmidt, 2005), and his claims to knowledge of women's bodily functions and needs. Jai felt he was positioned on a gendered hierarchy in facility work, which resulted in what he regarded as double standards and several challenges at work. Vic reported a sense of being both (sexually) objectified and expected to do the heavy work (Hrženjak, 2013; Hussein et al., 2014; Vaccaro, 2011). These men commented on the ways they were positioned as interlopers in women's territory. They were, however, also given permission by their work to actively nurture and care about others, opportunities they embraced.

The body

Bodily processes are the repository of those "reminders of our shared inheritance with other animals [that] have become the subject of cultural taboos: sex, menstruation, pregnancy, birth, feeding, defecation, urination, bleeding, illness, and dying. Messy stuff!" (Suddendorf, 2013, p. 7). Physical manifestations of lack of control over bodily processes hark back to our animal nature, showing how narrow the gap might be between our ordered lives and chaos (Shakespeare, 1994). Society is presumed to need to "restrain the anarchic

⁸⁶ The silent presence of counselling-type services does not appear to be satisfactory.

potential of the human body, to delimit bodily borders”, to clarify “where I stop and you begin” (Epstein, 1995, p. 185), driving at least some of the tasks care and support workers do to enable clients’ and residents’ satisfactory frontstage performances. Denial of the body may shore up a ‘normal’ identity, creating distance from “those feelings, processes or characteristics with which non-disabled society cannot deal” (Shakespeare, 1994, p. 287), but shields against the evidence of our mortality, fragility and vulnerability (Isaksen, 2002; Weicht, 2011) can only ever be temporary and fragile.

While workers risked social “contagion” (Epstein, 1995, p. 186) through their intimate relations with “*every fluid that comes out of [the] body*” (Jai), those workers with greater agency saw this as an opportunity for deeper connection. Body work, backstage, was a site where one might experience intimacy and cast aside the rules that constrain frontstage performances. Being together in the mess of the body made recognition more possible. The study found substantial evidence that for many participants, body work created an opportunity to be more authentic with one another. Workers used versions of the phrase, ‘There but for the grace of God go I’. They were candid about the intimacy of body work, the *shared* experience of leaks, erratics and accidents. Their integration of the ‘messy stuff’ was comfortable and comforting. Anita, Brian, Jai, Lilla, Vic, Shirley, Joanna, Miriam and Leonie saw that, as Anita put it, “*we are all human; it all happens to us*”. Their way of thinking gave ease to clients. Raphael, too, spoke with admiration of workers for whom there was “*no such thing as yeuch*”, who had “*no boundary at all on normality*”. But there was also ease being created for workers, some of whom seemed to be able to be themselves more deeply. In the backstage, they were allowed to be more candid as well as more nurturing towards other adults than is allowed in public frontstage settings. And death and laying out—which is perhaps the most extreme form of body work—were universally spoken of as privileges and opportunities to honour the person.

Being together in body work allowed recognition—at all three levels: we are all like this.⁸⁷ This comfort was not shared by Tilda, who frequently expressed disgust.⁸⁸ The physical closeness and intimate body work of care and support present a rare opportunity for two people to experience mutuality. They can both cast off the “*yeuch*”, the ‘normal’, and notions of dignity that rely on immaculate frontstage performance. Instead, dignity arises from authenticity and recognition.

Agency

For some workers in the study, the structural forces of class, gender, institutions, political settings and life chances presented only occasional or little threat. They demonstrated their agency (see footnote 10, p. 27) through the attention they could give the other, and through being effective in support. But for others, structural forces combined to repress agency, such that it was clear these workers did not understand themselves to be “the author of [their] acts” (Benjamin, 1988, p. 21). The failure of self-recognition that they experienced played out in agency-seeking behaviours like doing extra, unpaid work, advocating on clients’ behalves, demonstrating poor self-care, or in rigid rule-following and the imposition of their own (or the organisations’) will and norms.

Several workers reported (and I witnessed them) doing extras. They stayed late, or called in to complete jobs, unpaid and unrecorded by organisations. I speculate that this was a source of agency for them, a means to secure the presentation of self they desired, as competent and caring. As well as gaining a

⁸⁷ One might compare this with childish thinking about the Queen. Her body is utterly out of bounds and its processes somehow not human. She is disembodied and untouchable. And, we can never recognise her.

⁸⁸ Interestingly, feelings of disgust have recently been found to be associated with a self-protection response, with consequential self-interested and unethical behaviour (Winterich, Mittal, & Morales, 2014).

form of self-confidence from doing a satisfactory job, they could also sense themselves as a “doer who does” (Benjamin, 1988, p. 21), experiencing person-to-person recognition from the client and the solidarity of being essential to a larger project. Advocacy, similarly, was a means by which workers could feel valuable and make a claim to moral authority. Advocating demonstrated to themselves and to organisations that they understood a clients’ needs, for example; it was in part a quest for their own, the clients’, and a wider form of recognition.

These ways of seeking agency may be seen as beneficial to others (at least superficially), and enabling of both worker and client. Yet they are potentially risky to both, since they entrench low wages and the status of care as a sort of natural role for which there need not be financial compensation, effectively undermining agency. As well, extras and advocacy can position the client or resident as having no other avenues through which to claim an ordinary life, a kind of marginalisation. Doing extra, unpaid work also flagged poor self-care. These were workers who placed their needs for reasonable pay and working hours, and for ‘down-time’, below the perceived needs of clients. Those who did extras joked about having no social life, but they also reported several bouts of sick leave during the study and talked about depression or ‘feeling low’, consistent with literature reporting that aged care and disability support workers are at increased risk of depression, especially where clients or residents may be abusive (Ahlström & Wadensten, 2010; Geiger-Brown et al., 2007; Madsen et al., 2012).

Dementia and significant cognitive impairment present specific challenges. Beryl, the Shore View resident whom Tilda reported as being frequently accusatory and “*brutal*”, failed to recognise Tilda. Some of Beryl’s reactions may reflect a dementia-related loss of empathy, or it may be that Beryl had implicit memories (see Sabat, 2006) of Tilda’s mocking and dismissive (misrecognition)

behaviour towards her and was reacting against those humiliations. In order to treat Beryl as a sovereign other, Tilda needed to rely on her own agency and self-recognition, or she needed to feel supported by colleagues and superiors (solidarity), by a significant other (love), and by society (rights). But the series of moral injuries, poor life chances, and the low status and pay of her work combined to leave her with few resources for self-recognition. Other workers with little access to economic, cultural or educational resources seemed to be protected by their social supports; they were able to assume sovereignty in the other and to recognise them. Their reported responses to people with severe manifestations of dementia were very different from Tilda's.

It may be significant that none of those workers who seemed to exercise the most agency did extras, though most did at least some advocating. Six workers in particular—Joanna, Ruby, Vic, Brian, Jai, and Leonie—demonstrated agency. They did so in their resistance to what they saw as demeaning or other unfair employer practices. None of them did extra, unpaid work. They were attentive to their own, other workers' and clients' well-being and presentation of self.⁸⁹ They believed in their value as workers in their role, but were not defined by it. As well, all had completed (or were completing at the time of the study) higher education, and all had supportive relationships with family or friends, and with clients. With the possible exception of Brian, all were also at home in a middle-class milieu, where they had cultural and educational capital.

Agency and self-recognition were demonstrated in workers' preparedness to take care of the self. Such recognition allows people to "make use of their autonomy and, accordingly, recognize each other as free beings" (Honneth 1997, p. 20). Without it, recognition of the other was compromised (Benjamin,

⁸⁹ These reports were corroborated—sometimes by clients, sometimes by my observations (before the event) and sometimes by co-workers who were unaware of these workers' participation in the project.

1988; Honneth, 1996, 1997).

Forces acting on recognition: Summary

What factors had made it possible for participants to recognise the other and treat them in ways that demonstrated and enabled love, rights and solidarity?

Care and support workers typically have low educational and socio-economic status (see Chapter 2). While they may be employed to support clients' and residents' physical and cognitive needs, they may regularly support people who have had more education, are of a higher socioeconomic status, and who have greater social and cultural capital. Yet clients and workers are often together in having lives that are complex, unreliable, and peppered with seemingly random accidents and events. In discourses that valorise an economic measure of validity or citizenship, workers and clients are viewed as sub-optimal, never approaching the hegemonic ideal. They are untouchables together. They are linked by their proximity to, and tenuous protection from, chaos,⁹⁰ and their shared marginal position is exacerbated by stigmatising media and policy discourses.

Recognition and misrecognition in action

Each person has an "I" that is desired, congruent; we do (or try to do) things that match and maintain that "I", and rely on others to confirm our presentation. When something impairs our ability to present that "I", we can be assisted to live it. Thus, our construction of self is a co-construction and relies on the other to 'get' who they are with—to recognise them. The ultimate, most all-encompassing form of recognition described by Honneth is the recognition that one's "capabilities are of constitutive value to a concrete community"

⁹⁰ I am grateful to Dr Chris Lawrence for the term "chaos class"; it can be more descriptive than the current 'precariat' (pers. comm., 2015). Ideas of precariat and chaos class rest, somewhat unrealistically, on a presumption that the 'norm' is control and order (see Coleman, 2001).

(1997, p. 30), a ‘solidarity’ that is built on ‘love’ and ‘rights’. Our duty in interaction is to “demonstrate solidarity” (1997, p. 32). This is the “special consideration we owe to each other insofar as we participate jointly in the realization of a project” (p. 32). In aged care and disability support, the jointly realised project is the presentation of an internally consistent and externally competent self *by both worker and client*.

For it is only due to the cumulative acquisition of basic self-confidence, of self-respect, and of self-esteem—provided, one after another, by the experience of those three forms of recognition—that a person can come to see himself or herself, unconditionally, as both an autonomous and an individuated being, and to identify with his or her goals and desires. (Honneth, 1996, p. 169)

Workers and clients are co-conspirators in the events and tasks that enable each other to be the person they feel comfortable being; this both requires and fosters recognition. They are co-creative; collaborators in the presentation of self.

Implications

Implications for conceptualisations of care

At the start of this study, I had some hunches about workers, about interactions between workers and clients, and about practice as sources of meaning and identity. Was care a loving act or was it the oppressive and patronising entrenching of vulnerability and victim-hood? At its end, the findings present care as indeed central, but it was not care in the performance of tasks—even when conducted from a caring *about* perspective. Bathing, cooking or cleaning, and efficient support were not evidence of care. Care in this study was indivisible from recognition. It was a mutual and co-creative project of the self. Those participants who were able—or enabled—to regard one another as sovereign others, to recognise their own value and the value of those with whom they worked—cared in turn by enabling the presentation of the other’s desired self.

This way of theorising care builds on existing understandings that frame care as a product of relationship (e.g., (and see, Christensen, 2005-2006, 2009, 2010, 2012; England, 2005; Featherstone, 2010; Fine, 2007a; Fine & Glendinning, 2005; Folbre & Olin Wright, 2012; Guldvik et al., 2014; Hochschild, 2002; Isaksen, 2002; Lappalainen & Motevasel, 1997; O'Dowd, 2012; Wærness, 1984, 2004). It describes the conditions under which the mutual and co-creative project can flourish. This study's addition of recognition theory enables care to be situated within both intimate (love) and broader (rights and solidarity) social formations. In doing so, it demonstrates the overall negative role of existing social constructions of disability and aging, as well as the opportunities care and support interactions offer for deep and rich human engagement and the maintenance of personhood (Guldvik et al., 2014)—for both actors. This, in turn, makes it possible to identify ways to enhance recognition for the work and its participants, and thus support this mutually co-creative project of the self.

It was also apparent in the present study that this mutual project was unaffected by whether the client and workers were involved in disability support or aged care. This accords with the fact that workers may work in both roles concurrently, and that residential aged care was a starting point for many workers in this study. It is more surprising, perhaps, if one remembers that aged care and disability support have historically had very different attitudes to 'care'.

Implications for organisations: Practices in aged care and disability support

Applying recognition theory made clear the role of organisational practices and government policy in enabling or disabling workers and clients. Organisational practices were causing moral injury to clients and workers. Providers repeatedly demonstrated that they did not regard workers or clients as sovereign others, deserving of recognition—love, rights and solidarity. Workers and clients were pushed around, sometimes exploited, and frequently ignored.

Their needs were met intermittently, and their rights treated casually. Overall, organisations demonstrated low levels of trust in the people who worked for them and the people they theoretically worked for, their clients, and the trust they did show was decidedly bounded. Workers were trusted to go into people's homes, to cook, clean, support, and 'care for', but what they reported was sometimes ignored, their grief and other emotional trauma often went unnoticed, and their instances of poor self-care seemed taken for granted. Did their employers believe that the low numbers using employer-provided psychological (EAP) supports meant that the crises and deaths that workers were so close to had no impact?

This study is not the first to suggest that work environments for care and support workers need to provide relative autonomy, opportunities to display and have valued their skills and judgment, and support for their emotion management and labour work (Gray-Stanley et al., 2010; D. King, 2012). Offering workers better support for enhancing the relational aspect of work has been proposed as a means to increase the satisfaction and dignity of this work (Delp, Wallace, Geiger-Brown, & Muntaner, 2010). Taken together, these findings mean that organisations, in the first instance, need to find ways to provide opportunities for workers' emotion management and emotion work skills to be acknowledged and nurtured. Further, workers are in fact the eyes and ears—and the hands—of organisations. They have knowledge, judgement and skills that are specialised and valuable; these receive too little recognition. Organisations need to demonstrate that they take seriously and trust workers' reports of client or resident needs. Where workers (and clients) had sufficient resources or support for their own self-recognition, there appeared to be no need for a beneficent third party, attentive to the interests of both parties (Christensen, 2010). Organisations could do a great deal more to recognise workers and clients, perhaps especially at the rights level.

Further, organisations can reduce the present ways in which workers' wages are undermined (by rostering and travel costs, for example). Organisations set daily limits on travel reimbursement, but roster workers with little apparent thought for their capacity to absorb (even temporarily) the costs of long journeys. They swap package hours between clients, and rely — whether knowingly or not — on the unpaid and unrecorded extra work done by workers to make sure the needs of clients are being met.

More broadly, one might hope that organisations could overcome the pressures of competition and work together to lobby governments — and shift the public discourse — so that downward pressures on already scant funding are reversed. Setting policy that forces organisations to compete is a cynical strategy to reduce costs associated with enabling parity of participation (Fraser, 2000) for all citizens. If, on the other hand, the organisations 'fessed up' to one another, they could present a united front to counter at least some of the structural forces that shape their sector.

The combination of a disempowered and misrecognised workforce, somewhat compliant (and misrecognised) clients,⁹¹ and provider organisations blinkered by the pressures on their own survival and engaged in an increasingly ruthless price war mean that governments can continue to squeeze the sector. The wage increase awarded to some workers in this study in 2012 was ineffective and could even arguably be seen as entrenching the gendered and low status position of workers and of clients. One might speculate that the recent small increase in the proportion of men in this workforce may be reversed. Workers' and clients' welfare are, as this study has shown, inextricably linked; this implies that unions, too, need to be involved.

⁹¹ The NDIS and CDC may empower clients, but the risks of unequal relationships (and thus misrecognition) are present.

Implications for policy: Consumer-directed models and recognition

The circumstances that have allowed and driven some poor organisational practices are now changing. This project took place as existing models of aged care and disability support funding were giving way to new, 'person-centred' and 'client-directed' models (CDC and NDIS). This study can be viewed, then, as a qualitative snapshot of how aged care and disability support work was organised and of the experiences of some actors in this play at the start of a new delivery system. Will CDC and the NDIS fulfil their promise of better targeted and more individually satisfactory experiences for clients? Will clients be enabled? And how will workers—who remain low status and marginalised—now fare under models that risk positioning them as commodities whose services can be bought and sold more readily than before. CDC and NDIS may be seen as atomising processes, models that do not reflect our embeddedness in social groups and the necessity of interaction as a site of recognition.

Commodification artificially empowers one side (clients). The value of workers is denied and the potential for mutual recognition undermined. Since I argue that enabling recognition may be essential to genuine and effective support provision, how will recognition fare if workers are further alienated from the meaningful co-creative possibilities of care and support work? The inklings of recognition present in this study may well lack the conditions in which to grow or flourish in this more commercial, competitive world of commodified workers, employer clients and brokering organisations.

The structural pressures experienced by organisations have hitherto been managed by means that sometimes result in moral injuries to workers and clients. The shift to client-directed models has been accompanied by increasing budget strictures and the looming possibility of collapses that could see the current variety of provider organisations replaced by a small number of very large for-profits (and not-for-profits that appear indistinguishable in actions

from the for-profits) that can afford to engage in price wars (see, for example, Greener, 2011; Hochschild, 2011; Wolton, 2013). Workers are unlikely to gain in such a circumstance (Rubery et al., 2015).

The substantial and unknown number of unpaid hours being provided have additional implications both for wages and conditions and for how policy is set. Workers are effectively working for a lower hourly wage than their on-paper wages and hours imply. Organisations and governments cannot estimate the actual client need, or the size and skills of the workforce required when the extras are not being measured. Under the new models, organisations will have much greater difficulty ignoring the workers' and clients' rule transgressions, and the loyalties fostered by workers' unpaid extras may also disappear.

Workers and clients value the non-instrumental aspects of the work—the emotions and relationships and sense of making a difference, of being people to each other. These recognition aspects are not included in any accounting for the costs of providing care and support. Indeed, Lappalainen and Motevasel (1997) describe the prevailing neo-liberal social policy model as being predicated on a distinctly traditional social set up in which caring is the role of family and friends, and belongs in the private sphere, where the stress is placed on 'love' (which informal care is claimed to provide while formal care does not). This formulation is resistant to calculating the costs and benefits of emotion work, thus denying it a market value and keeping wages for care and support workers low. Yet, such a measure would enable us to demonstrate more of the real productivity of people with disabilities as well as of workers.

Finally, solidarity relies on the absence of stigma around disability and ageing. Models of support and care that valorise getting younger people with disabilities into the workforce (or risk loss of benefits that barely sustain their access to ordinary life) and that push out retirement age with ideas of active or 'positive' ageing is creating new ways for clients and workers to fail. There are

many who have never, do not now, and can never match the *Homo economicus* (Houston, 2010) yardsticks of workforce participation and active aging — of lifting (economically) not leaning (Garner, 2014). The public conversation needs to change, such that the actors in care and support experience recognition.

Implications for methods and methodology

The sample of workers and clients in the study was skewed (see Chapter 3). The recruitment methods followed meant that only people who could read the printed material or who attended a session where I talked about the project were recruited. I also excluded people who were unable to consent. Thus, the range of clients, and of workers was narrowed. Further, workers and clients demonstrated an at least moderate level of agency by becoming involved and being willing to be interviewed — a daunting prospect for many people.⁹² The truly disempowered remained out of reach. This is a failing (and, indeed, as I now understand, a form of misrecognition) that needs to be ameliorated but that continues in part because of conceptualisations of protection and vulnerability. For all these reasons, what the participants told me and what I observed cannot be presumed to be generalisable beyond these circumstances.

There is a proviso, however. The consequences for workers and clients of the poor self-recognition Tilda (but also Blanche and Tash) demonstrated were clear. These three women more closely resembled the typical worker (Chapter 2) than did, for example, Joanna, Vic or Anita. This means that the findings of moral injury and its consequences are probably more pressing for the disability support and aged care workforce as a whole than they were for this study's sample.

⁹² Shirley expressed her nervousness about being interviewed, which was overcome only by her concern that voices like hers be heard.

Repeated interviews

Without repeated interviews and conversations with the participants, matters of presentation of self may well have remained surface performances. With our repeated contact, I began to reflect both on my own and on participants' performances, and was shown at least some of the deeper, backstage selves. A simple piece of evidence in support of this claim is the steep decline in the number of instances of the phrase "*Can I just say*" from my first to last interview with one participant (reported in Chapter 3). Repeated interviews also enabled me to check that I had understood what participants had said, talk over how I was thinking about the data, and gain further information about what I had observed. All such conversations added layers of richness as well as sparking several discussions about the "that's funny" moments.

Visual methods

This study used two visual methods to gather data: photo-elicitation and photo-voice.

Photo-elicitation proved a valuable additional prompt in interviews with workers. They seemed unsure when first presented with the photo prompts, almost as if they thought I was seeking right or wrong responses. To reassure them, I showed my own lack of knowledge by asking them about the instruments of support (hoists, for example, or walkers) some photographs depicted and they began to go into detail about what each object was used for and what they liked or disliked about them. The ice broken, they then shuffled through the photographs, talking in detail about aspects of their work that we had not spoken about before. Thus, Vic talked about authentic support versus patronising projects that showed workers in a good light but were meaningless to clients. Brian and Lilla talked about practices around food, Tash alerted me to labels (e.g., "*he's a hoist*"), and Tilda exposed the dilemma presented when

clients presumed the uniform she was wearing meant she was a nurse, with the medication and wound dressing privileges that entails. The photo prompts added data that may well have been missed.

I had hoped that photographs taken by the participants would show aspects of the work and their relationship that they took for granted. But there was also a risk that things they did not mean to expose would be shown to me. As Sontag wrote, photographs “were a record of the real—incontrovertible, as no verbal account, however impartial, could be—since a machine was doing the recording. And they bore witness to the real—since a person had been there to take them” (Sontag, 2003, p. 23). My hope for the method was fulfilled, but so was my concern about exposure. The photographic data showed things that were usually hidden, revealing more than the photographers and their subjects intended. This was reminiscent of the impact of my audio-recorder: it made Shirley more nervous and temporarily silenced Raphael, perhaps because it would be a permanent record of his Parkinson’s disease-affected speech.

The technological challenges of using a digital camera were, contrary to my concerns, the least confounding aspect of inviting dyad members to take photographs. Only three of the dyads took up the invitation—Olivia and Joanna, Sally and Anita, and Evelyn and Blanche—and only two completed portfolios of images. Sally and Anita’s cameras were lost when Sally died. The technology was inappropriate for use by some participants, and some simply did not want to take part. But, how Evelyn and Blanche used the cameras raised ethical problems that need consideration. Although the women had given consent to one another to take photographs, neither was happy with the results and it appeared that one sequence of images had been taken against the subject’s wishes. While this was revelatory for the project, it put their relationship on a different footing.

Future research

The foregoing suggests two directions for future research. Firstly, a means to place a monetary value on recognition (and the emotion work required) could be ascertained. I suggest that the 'market' or exchange value of emotion work shows up when it is neither paid for nor treated as a marketable skill to be developed and sustained. It is likely that measures of workers' and clients' physical and emotional wellbeing could be used to test the outcomes of an intervention that supported workers' own emotional management and labour. The dollar value in worker absenteeism and turnover, and in clients' health costs could be calculated. By these means, to use a martial arts analogy, the force of neo-liberal policy might be used against itself.

Secondly, the absence of care and support from community to sector, from policy makers to sector, and from sector to employees and clients is a major source of moral injury and misrecognition in aged care and disability support. Indeed, there is some evidence in the present study of a 'don't care chain', such that recognition has no formal place in how the actors in the sector interact. A discourse analysis of policy, peak body and organisation documents could be conducted to determine the prevalence of stigmatising and disrespectful conceptualisations of workers and clients (and their reverse)—but also to one another—with a view to designing interventions that could reshape language and discourses.

Concluding remarks

As I was analysing the data from this study, I started reading John Berger and Jean Mohr's 1967 book, *A Fortunate Life: The story of a country doctor*. I had picked it up because some phrases in a review of it, prepared for the book's reprinting, echoed things I was reading in the data. The book's central figure (a country GP) was, for example, overwhelmed by the "suffering of his patients and his

own sense of inadequacy" (Francis, 2015, p. 3 of 5), just as Anita had said she sometimes was. The GP was, according to Berger, "acknowledged as a good doctor because he meets *the deep but unformulated expectation* of the sick *for a sense of fraternity. He recognizes them*" (J. Berger & Mohr, 1969, p. 76) (emphasis added). Berger and Mohr's intensely political book harked again and again to the centrality to the doctor's practice of not "maintaining his imaginative distance", but coming "close enough to recognize the patient fully" (1969, p. 113). Here was Honneth's recognition: love, rights and solidarity. It was present in Raphael's plea for workers for whom there was "*no such thing as yeuch*". Brian understood it when he said that clients were "*not a bit of paper and they're not a list of tasks*", and that working together was "*a journey*", "*an unscripted story*" for which one could not plan, but only pay attention. It was Anita's "*we are all human. It all happens to us*", and Jai's idea of "*becoming people to each other*". Those workers were present in this study, and their work for recognition was rewarded handsomely in rich, collaborative, projects of the self.

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Appendices

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Appendix A. Project recruitment posters and fliers

Noticeboard posters (original: A3 size)—Aged care and disability support workers

Do you work providing care and support to people with disability or frail elderly people?

I am interested in understanding the people behind the statistics in government reports that tell us we'll need more than **half a million** more people in your industry by 2050! What do you do, and how do you feel about your work? What are the **stories behind the numbers**?

If you are a community care worker, personal care assistant or other person working with people with disability or those who are frail due to age, in their homes, in day-centre or residential facilities, I'd like to talk to you.

My name is Susan Banks and I am a post-graduate student at the University. I want to interview and observe workers to understand what you do and why you do it. If you are interested in finding out more about my study—and possibly taking part in it, I'd love to hear from you. Please contact me on 6226 2914, [mobile], or by email: susan.banks@utas.edu.au



What do community care workers and personal care assistants do, and how do they feel about their work? **What are the stories behind worker and client numbers?**

If you work with people with disability and/or people who are frail due to age, either in their homes, in day centres or in residential facilities, I'd like to talk to you. I'm interested in understanding the people behind the statistics in government reports that tell us we'll need more than **half a million** more people in your industry by 2050!

My name is Susan Banks and I am a post-graduate student at the University. I want to interview and observe workers who provide support and care work to understand what you do and why you do it. If you are interested in finding out more about my study—and possibly taking part in it, I'd love to hear from you. Please phone or email me:

6226 2914; or [mobile number]; susan.banks@utas.edu.au

Please take a tear off reminder ...



What do community care workers and personal care assistants do, and how do they feel about their work? **What are the stories behind worker and client numbers?**

If you work with people with disability and/or people who are frail due to age, either in their homes, in day centres or in residential facilities, I'd like to talk to you. I'm interested in understanding the people behind the statistics in government reports that tell us we'll need more than **half a million** more people in your industry by 2050!

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Do you work providing care and support to people with disability or frail elderly people?

I am interested in understanding the people behind the statistics in government reports that tell us we'll need more than **half a million** more people in your industry by 2050! What do you do, and how do you feel about your work? What are the **stories behind the numbers**?

If you are a community care worker, personal care assistant or other person working with people with disability or those who are frail due to age, in their homes, in day-centre or residential facilities, I'd like to talk to you.

My name is Susan Banks and I am a post-graduate student at the University. I want to interview and observe workers to understand what you do and why you do it. If you are interested in finding out more about my study—and possibly taking part in it, I'd love to hear from you.

Please contact me on 6226 2914, 0458 007 103, or by email: susan.banks@utas.edu.au



Newsletter and pigeonhole fliers and posters (original: A4 size)—Aged care and disability support workers

Noticeboard posters (original: A3 size)—Aged care and disability support recipients

Do you receive assistance from a community care, personal or extended care worker?


I am interested in understanding the people behind the statistics in government reports that tell us we'll need **half a million** more people providing these services by 2050! What do these services look like to recipients?

What are the stories behind the numbers?

If you are a person who receives services from a community care worker, personal care assistant or other worker, in your home, a day centre or residential facility, *I'd like to talk to you.*

My name is Susan Banks and I am a post-graduate student at the University. I want to interview and observe workers to understand what you do and why you do it. If you are interested in finding out more about my study—and possibly taking part in it, I'd love to hear from you.

Please contact me on **6226 2914, 0458 007 103**, or by email: susan.banks@utas.edu.au
(please tear off a reminder, below)



What do community care workers and personal care assistants do, and how do they feel about their work? *What are the stories behind client and worker numbers?*


If you receive domestic assistance, personal care, social support or respite services, at home or in a day centre or other facility, I'd like to talk to you. I want to find out more about the working lives of people providing paid care or support. By understanding this work more fully, better ways to support workers and recipients may be identified.

"Based on estimated demand projections and assuming models of care are maintained, there will need to be approximately **827,000** aged care workers by 2050"
(Using Longer, Living Better, 2016, p. 75)

My name is Susan Banks and I am a post-graduate student at the University. I want to interview and observe workers and recipients in care and support. If you are interested in finding out more about my study—and possibly taking part in it, I'd love to hear from you. Please phone or email me:

6226 2914; or [mobile number]; susan.banks@utas.edu.au

Please take a tear off reminder ...



... (repeated text for reminder strip) ...

... (repeated text for reminder strip) ...

Do you receive assistance from a community care, disability support, personal or extended care worker?


I am interested in understanding the people behind the statistics in government reports that tell us we'll need **half a million** more people providing these services by 2050! What do these services look like to recipients?

What are the stories behind the numbers?

If you are a person who receives services from a community care worker, personal care assistant or other worker, in your home, a day centre or residential facility, *I'd like to talk to you.*

My name is Susan Banks and I am a post-graduate student at the University. I want to interview and observe workers to understand what you do and why you do it. If you are interested in finding out more about my study—and possibly taking part in it, I'd love to hear from you.

Please contact me on **6226 2914, 0458 007 103**, or by email: susan.banks@utas.edu.au




Do you receive assistance from a disability support, community care, personal or extended care worker?

If you receive assistance (including personal care, social support or respite services), in a facility, at home, in a day centre or supported accommodation, I'd like to talk to you. I want to find out more about the working lives of people providing paid care or support, and the way they work with recipients. By understanding this work more fully, better ways to support workers and recipients may be found.

My name is Susan Banks and I am a post-graduate student at the University. I want to interview and observe workers and recipients in care and support. If you are interested in finding out more about my study—and possibly taking part in it, I'd love to hear from you.

Please phone or email me:

6226 2914; or 0458 007 103; susan.banks@utas.edu.au



Newsletter and pigeonhole and fliers posters (original: A4 size)—Aged care and disability support recipients

Appendix B. Information Sheets and Consent Forms

All participants were given/read a project outline, as well as the relevant information sheet and consent form.

Stories of support and care—exploring practice and meanings of care for workers providing services to people with disability or the frail aged

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Stories of support and care—Project outline

This project explores the practice and meanings of care for workers providing services to people with disabilities and the frail elderly. The focus is on non-clinical workers—PCAs/ECAs/LLOs, community care workers and disability support workers. This sector of the health and social care labour force has received little attention, other than statistical. The statistical data tells us that the need for these workers in these roles is high and growing, that they are often older than the average working person in Australia, and that they are most often women. We do not have evidence, however, about how they see their role, the people they work with, and themselves in that work. What meanings does the work give them?

Workers and recipients of aged care or disability services—both in facility, day centre and at-home settings—will be invited to take part in the study. Their involvement will include formal and informal conversations with the researcher, as well as (some of) the work being observed.

There are several potential benefits from the project. First, focusing on the workers signals to them that what they do is important; reducing worker and recipient invisibility and marginalisation is an important potential outcome. Second, greater understanding of the motivations and rewards, and the disadvantages of the work could provide employing organisations, and representative bodies (i.e. unions), with enhanced capacity to meet workers' needs. Third, knowledge of workers' understandings of and responses to recipients with different impairments may lead to more tailored training and protocols, and thus better working conditions and recipient outcomes.

For the wider community, an enhanced understanding of the perceptions, motivations and rewards for the workers providing services to these recipient groups will contribute to a better informed debate and—it is hoped—better workforce policy and outcomes. Further, a more sympathetic public and health professional response to these essential workers could enhance recruitment and retention.

Human Research Ethics Committee approval: H0013031



Stories of Support and Care—Information sheet for workers

You are invited ...

"Stories of Support and Care" is a study being conducted by a PhD student at the University of Tasmania's School of Sociology and Social Work. The study is focused on the work done by people who work with the frail elderly, and/or people with disabilities. The researcher is interested in the work, and in workers' views of the work and of the people they provide services to.

The student researcher, Susan Banks, is being supervised by Dr Emily Hansen and Associate Professor Douglas Ezzy. If you would like to talk to Emily or Doug, their contact details are given at the end of this sheet.

What is the purpose of this study?

The aim of the study is to find out more about the working lives of people doing non-clinical care and support work in facilities and in the community with clients with different needs. By understanding this work more fully, better ways—for organisations, other workers and clients, communities and governments—to support workers by may be identified. The research is hoping to build up a rich, 'warts-and-all' description of your working life.

Why have you been invited to be in this study?

You have been invited to participate because you are an adult providing support or care services to disabled and/or frail aged people. Your involvement is completely voluntary, and if, at any time, you decide not to continue participation, you may withdraw with no consequences.

What will you be asked to do?

You will be involved in two ways.

First—you will be invited to take part in a series of interviews. Participants will be interviewed by the researcher 3 or 4 times over about 6 months. The first interview will be quite short (no more than 30 minutes) and is intended to give you and the researcher a chance to get to know one another, and for you to give the researcher an idea of your work schedule and clientele. The other interviews will be longer (up to 1.5 hours), so that more detailed discussion can happen. All interviews will be recorded using a digital recorder so that the researcher doesn't miss anything. Recordings will be written up by the researcher and your name (and the recipients') will be removed. Some things from the interviews will be talked about when next we meet, so the researcher can check that she has understood what was discussed. You are not obliged to answer any question you do not wish to answer and can pause, postpone or stop the interview at any time.

Second—because it is important that the researcher understands as much about the work as possible, she would like to accompany you as you work—but *not during provision of services*. So she would like to come with you as you visit different recipients (or be at the facility where you work), and talk to you between services or during breaks. She will take notes, to make sure she remembers properly. The notes the researcher makes won't use your name or any recipient's name, or the name of the facility or organisation you work for. The researcher will ask the organisation for permission to be there.

Consent

It is important that participants consent to taking part in research. This is to make sure that the researchers conduct an approved study, that you have understood what is involved, and that you understand you are free to withdraw at any time. A consent form will be given to you for signing at your first meeting with the researcher.

Are there any possible benefits from participation in this study?

Because the work you do and your role in the health and support system is not well known to the community, publishing the results from this study is an opportunity for the community, provider organisations, unions, policy makers and other researchers to better understand the work, the workers, and the ways in which services are provided to recipients.

Human Research Ethics Committee approval: H0013031

Are there any possible risks from participation in this study?

Because of the nature of your work, it may be distressing to recall particular experiences. If you do become distressed as a result of participation, you may wish to access counselling services without needing to contact the researcher, for example:

Lifeline: 13 11 14

Grief line: 03 9596 7799

What if I change my mind during or after the study?

You are free to pull out of the study at any time, and you don't need to give the researcher a reason. As well, if you want to remove the information gained from you from the study, this will be possible until it is combined with the information from other participants. Because what you say and do during the study will not have your name on it, and because it is part of a big pool of information, it won't be possible to remove that information.

What will happen to the information when this study is over?

All the recordings, researcher's observation notes, and interview transcripts will be kept in the locked office of Susan Banks, and/or as electronic files in a password-protected secure server. This material will be kept for 5 years (the amount of time recommended by the university) from the date of first publication and then will be deleted or shredded. Susan is the only person who will be able to read, view or listen to the material. The material is treated with strict confidentiality. No worker, recipient, organisation or facility names will be revealed.

How will the results of the study be published?

The research will be written about in the student researcher's doctoral thesis, and in articles and conference presentations. It may also be discussed in other sorts of publication, like newspaper opinion pieces or online discussions. Always, the identity of the workers, their clients and the facilities and organisations involved remains confidential. As well, the student researcher will give you short summaries of the study's findings before the project is completed.

What if I have questions about this study?

Susan Banks can be contacted at the university of Tasmania (03 6226 2914), or by email (susan.banks@utas.edu.au). The student's supervisors can be contacted as follows: Dr Emily Hansen (03 6226 1782; emily.hansen@utas.edu.au); Doug Ezzy (03 6226 2330; douglas.ezzy@utas.edu.au). This study has been approved by the Tasmanian Social Sciences Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. Please quote ethics reference number H13031.

Thank you. Please keep this information sheet if you wish.

.....
Susan Banks

Student researcher

.....
Dr Emily Hansen

Principal supervisor

Human Research Ethics Committee approval: H0013031

1. I have read and understood the 'Information Sheet' for this project.
2. The nature and possible effects of the study have been explained to me.
3. I understand that participation in the study involves being interviewed, and being accompanied by the researcher during some work sessions.
4. I understand that interviews will be audiorecorded.
5. I understand that participation involves the risk(s) of recalling some potentially upsetting experiences in relation to providing care or support to people with disability or frail elderly people, and that further support is available to me, should I require it.
6. I understand that all research data will be securely stored on the University of Tasmania premises for five years and will be destroyed when no longer required.
7. Any questions that I have asked have been answered to my satisfaction.
8. I agree that research data gathered from me for the study may be published provided that I cannot be identified as a participant.
9. I understand that the researchers will maintain my identity as confidential and that any information I supply to the researcher(s) will be used only for the purposes of the research.
10. I agree to participate in this study and understand that I may withdraw at any time without any effect.

Name of Participant: _____

Signature: _____

Date: _____

Statement by Investigator

☐ I have explained the project & the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation

If the Investigator has not had an opportunity to talk to participants prior to them participating, the following must be ticked.

☐ The participant has received the Information Sheet where my details have been provided so participants have the opportunity to contact me prior to consenting to participate in this project.

Name of investigator _____

Signature of investigator _____

Date _____

Human Research Ethics Committee approval No. 13031

Stories of support and care—Project outline

This project explores the practice and meanings of care for workers providing services to people with disabilities and the frail elderly. The focus is on non-clinical workers—PCAs/ECAs/LLOs, community care workers and disability support workers. This sector of the health and social care labour force has received little attention, other than statistical. The statistical data tells us that the need for these workers in these roles is high and growing, that they are often older than the average working person in Australia, and that they are most often women. We do not have evidence, however, about how they see their role, the people they work with, and themselves in that work. What meanings does the work give them?

Workers and recipients of aged care or disability services—both in facility, day centre and at-home settings—will be invited to take part in the study. Their involvement will include formal and informal conversations with the researcher, as well as (some of) the work being observed.

There are several potential benefits from the project. First, focusing on the workers signals to them that what they do is important; reducing worker and recipient invisibility and marginalisation is an important potential outcome. Second, greater understanding of the motivations and rewards, and the disadvantages of the work could provide employing organisations, and representative bodies (i.e. unions), with enhanced capacity to meet workers' needs. Third, knowledge of workers' understandings of and responses to recipients with different impairments may lead to more tailored training and protocols, and thus better working conditions and recipient outcomes.

For the wider community, an enhanced understanding of the perceptions, motivations and rewards for the workers providing services to these recipient groups will contribute to a better informed debate and—it is hoped—better workforce policy and outcomes. Further, a more sympathetic public and health professional response to these essential workers could enhance recruitment and retention.

Human Research Ethics Committee approval: H0013031



Stories of Support and Care—Information sheet for workers and for recipients

You are invited ...

You are invited to take part in a research project called “Stories of Support and Care” which is focused on the work done by community care workers, support workers and personal care assistants with the frail elderly, and/or people with disabilities. The researcher is interested in the work, and in workers’ and recipients’ views of the work. The study being conducted by Susan Banks, who is a PhD student in the University of Tasmania’s School of Sociology and Social Work. Susan is being supervised by Dr Emily Hansen and Associate Professor Douglas Ezzy. If you would like to talk to Emily or Doug, their contact details are given at the end of this sheet.

What is the purpose of this study?

The aim of the study is to find out more about the working lives of people doing non-clinical care and support work in facilities and in the community with clients with different needs. By understanding this work more fully, better ways—for organisations, other workers and recipients, communities and governments—to support workers by may be identified. The research is hoping to build up a rich ‘warts-and-all’ description of workers’ working life.

Why have you been invited to be in this study?

Part of the study is about the relationship between workers and recipients, so several pairs of recipients and workers are taking part. You have been invited to participate because you are an adult who provides support or care services to disabled and/or frail aged people **or** because you are an adult who receive services from a worker. Your involvement is completely voluntary, and if, at any time, you decide not to continue participation, you may withdraw with no consequences.

What will you be asked to do?

People who take part in this project will be involved in three ways.

First—Interviews. Everyone will be invited to take part in one or more interviews. Workers will be interviewed by the researcher 3 or 4 times over about 6 months, and recipients will be interviewed at twice. The first interview will be quite short (no more than 30 minutes) and is intended to give you and the researcher a chance to get to know one another, and for you to give the researcher an idea of how often the services are provided; this will help in drafting a timetable for the observation part of the study. The other interviews will be longer (up to 1.5 hours), so that more detailed discussion can happen. All interviews will be recorded using a digital recorder so that the researcher doesn’t miss anything. Recordings will be written up by the researcher and your name will be removed. Some things from the interviews will be talked about when next we meet, so the researcher can check that she has understood what was discussed. You are not obliged to answer any question you do not wish to answer and can pause, postpone or stop the interview at any time.

Secondly—Images. You will be invited to take photographs of the service provision. Not everyone in the study needs to do this, but it will be helpful if you can. If you want to, the researcher will give you an inexpensive camera, and talk to you about the photographing part of the study during your first interview. It is important that both worker and recipient are comfortable with this part of the project, and that no photographs are taken without the consent of the other person. The researcher will have the photographs developed as digital files, which she will share with you so that you can comment on them (or withdraw any or all of them from the study if you wish).

Finally—Observation. Because it is important that the researcher understands how the work is done, she will invite you to be involved in what is called ‘participant observation’. In participant

Human Research Ethics Committee approval: H0013031

observation, the researcher comes to one or more service sessions (like a student nurse or doctor might spend time with a GP as part of their training), or is around the facility where the work is done. Consent for this is necessary. If consent is given, the researcher will be in the background (unless you'd like her to help) and just see the work. She may take notes, to make sure she remembers properly. The researcher understands that some parts of the work are more private than others, and will be happy to leave the room if either the worker or the recipient wants.

The notes the researcher makes won't use your names, or the name of the facility or organisation, and will not include any information which would make it possible for you to be identified.

Consent and privacy

It is important that participants consent to taking part in research. This is to make sure that the researchers conduct an approved study, that you have understood what is involved, and that you understand you are free to withdraw at any time. A consent form will be given to you for signing at your first meeting with the researcher. It is also important that your privacy is maintained. For this reason, the researcher will ask you to suggest a name by which you will be identified in the study and in any publications that result from it.

Are there any possible benefits from participation in this study?

Because this work and its role in the health and support system is not well known to the community, publishing the results from this study is an opportunity for the community, provider organisations, unions, policy makers and other researchers to better understand the work, the workers, and the ways in which services are provided.

Are there any possible risks from participation in this study?

Because of the nature of this work, it may be distressing to recall particular experiences. If you do become distressed as a result of participation, you may wish to access counselling services without needing to contact the researcher, for example:

Lifeline: 13 11 14

Grief line: 03 95 96 7799

What if I change my mind during or after the study?

You are free to pull out of the study at any time, and you don't need to give the researcher a reason. As well, if you want to remove the information gained from you from the study, this will be possible until it is combined with the information from other participants. Because what you say and do during the study will not have your name on it, and because it is part of a big pool of information, it won't be possible to remove that information.

What will happen to the information when this study is over?

All the recordings, researcher's observation notes, negatives and copies of photographs and interview transcripts, and contact details will be kept in the locked office of Susan Banks, and/or as electronic files in a password-protected secure server. This material will be kept for 5 years (the amount of time recommended by the university) from the date of first publication and then will be deleted or shredded. Susan is the only person who will be able to have access to the material. The material is treated with strict confidentiality. No worker, recipient or facility names will be revealed.

Human Research Ethics Committee approval: H0013031

How will the results of the study be published?

The research will be written about in the student researcher's doctoral thesis, and in articles and conference presentations. It may also be discussed in other sorts of publication, like newspaper opinion pieces or online discussions. Always, the identity of the workers, their recipients and the facilities and organizations involved remains confidential. As well, Susan will give you short summaries of the study's findings before the project is completed.

What if I have questions about this study?

Susan Banks can be contacted at the university of Tasmania (03 6226 2914), or by email (susan.banks@utas.edu.au). The student's supervisors can be contacted as follows: Dr Emily Hansen (03 6226 1782; emily.hansen@utas.edu.au); Doug Ezzy (03 6226 2330; douglas.ezzy@utas.edu.au). This study has been approved by the Tasmanian Social Sciences Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. Please quote ethics reference number [H13031].

Thank you. Please keep this information sheet if you wish.

.....
Susan Banks
Student researcher

.....
Dr Emily Hansen
Principal supervisor

Human Research Ethics Committee approval: H0013031

Consent form—*Stories of Support and Care*: Workers and recipients

1. I have read and understood the 'Information Sheet' for this project.
2. The nature and possible effects of the study have been explained to me.
3. I understand that participation in the study involves being interviewed, that service delivery may be observed, and that both the worker and the recipient may take photographs of this service delivery. I also understand that people being photographed need to give their consent.
4. I understand that interviews will be audiorecorded.
5. I understand that participation involves the possibility of the researcher being present during normally private situations and that there is thus a risk of embarrassment. I also understand that I may ask the researcher to not be present at such times.
6. I understand that participation also involves the risk(s) of recalling some potentially upsetting experiences in relation to care or support, and that further support is available to me, should I require it.
7. I understand that all research data will be securely stored on the University of Tasmania premises for five years and will be destroyed when no longer required.
8. Any questions that I have asked have been answered to my satisfaction.
9. I agree that research data gathered from me for the study may be published provided that I cannot be identified as a participant.
10. I understand that the researchers will maintain my identity as confidential and that any information I supply to the researcher(s) will be used only for the purposes of the research.
11. I agree to participate in this study and understand that I may withdraw at any time without any effect.

Name of Participant: _____

Signature: _____

Date: _____

Statement by Investigator

- ☐ I have explained the project & the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation

If the Investigator has not had an opportunity to talk to participants prior to them participating, the following must be ticked.

- ☐ The participant has received the Information Sheet where my details have been provided so participants have the opportunity to contact me prior to consenting to participate in this project.

Name of investigator _____

Signature of investigator _____

Date _____

Human Research Ethics Committee approval: H0013031

Appendix C. Examples of first contacts with participants

Email exchange between participant and the researcher

From participant (email included some material he had written about support work):

this is from my mind drawn from what i now see i have been a carer for 13 years in community care and 9 years and 4 months in dementia specific care i hope this might give you something to think about 😊

Susan responded:

Hi [name]

Wow – thank you. I really appreciate this and am extremely interested in how carers think about and see the people they work with. Want to talk to me directly, perhaps? I am quite mild and would very much appreciate it AND it's important that the sorts of opinions you have are included! ... or actually, it would also be okay to just have an email conversation if that suited you ... What you have sent me is rich (I like this idea: "there's no one there to kick up a stink", for example). I do hope you could be in my study – the way you see the work is really interesting and would be good to be able to include. Anyhow, let me know ...

Best wishes and thank you!!

Susan

My office number on Tuesdays – Fridays is — :)

Participant responded:

susan i am pleased that my thoughts make you think. i an studying [name of course] and this week will be on placment so hope to ring you soon. 😊

Text message exchange between participant and the researcher

Hi Susan, not sure if too late with this response. My name is [name] and I work in aged care and I have for 11 years. I am extremely interested in your research

Susan: Hi [name]. Not too late. 😊 could we meet to see whether it will work for you? Monday is not good for me generally, but otherwise ... I should add that my study is of non-nursing workers. Great to hear from you. Cheers, Susan.

I am a carer One of the hard workers!!! [personal details removed]
Tuesday afternoon is good for me unless Monday late is an option.

S: Tuesday afternoon is perfect. What time and where suits you? I can come to wherever. Cafes can be good for first meeting : -)

Any time and almost anywhere whatever suits your schedule

S: How about zest at the state library at two thirty? Sound okay?

That is good. Are you on Facebook? If you are, you can check out my Facebook page and see my picture!

S: Hi [name]. Surname for facebook? 😊

[surname]

Text messages between participant and researcher

Good afternoon susan. It was good to briefly meet you. I would be very interested to be a part of your community care, disability and personal support research study. Providing I can remain anonymous and confidential. I would happy to arrange a time to meet you to get started. Regards [name]

Susan: Excellent and thank you. I enjoyed today. Would Monday be too soon for you? 😊

S: Hi again [name]. Timing is up to you of course, And confidentiality is very important to me too, so there are several things I do to guard your privacy. Will elaborate when we meet. Cheers Susan

S: Of course. Just let me know where and when you would like to meet, The only day I cant do is Tuesday. Have a nice weekend. 😊

Good evening susan. Can I reply next week regards [name]

S: Hi [name]. How are you going? Let me know when suits you to meet. :-) sorry. I am not nagging. 😊

Good evening susan. Sorry for not replying to yr text on the weekend however I had a personal crisis that I had to deal with. Sorry about that. I really do want to meet with you. Could we meet around 1pm on Wednesday 2nd October? If that suits you? Regards [name] :)

S: Sorry to hear you had a bad weekend [name]. The second of October sounds good. I will put it in my diary and contact you a couple of days before to work out where. Best wishes, Susan

Good evening susan. My home address is [address]. If u need to mail documents to me. Please use my mail address which is [address]. Here is my email address which is [address]. I look forward to seeing you on Wednesday 2nd of October at 1pm. Regards [name] 😊

S: Brilliant, thank you. Best

Appendix D. Links between participants and organisations

Table A.1. Links between participants and organisations

Key

RACF	Residential aged care facility
DRF	Disability residential facility
CC	Community care
DC	Day centre
GH	Group house
ILU	Independent living unit

	Clients/residents	Bill	Cornelia	Erica	Evelyn	Gerry	Laurence	Nicko	Norah	Olivia	Raphael	Sally	Winifred
Workers	Participants not in dyads		Crescent ILU						Cliveden RACF				
Anita												Hillcrest CC	
Blanche					Hillcrest CC								
Brian		Crescent CC											
Edwina							Harvest CC						
Jai	Tudor RACF												
Joanna										Hillcrest CC			
Justin						Peregrine GH							
Leonie								Private					
Lilla	Carey RACF												
Miriam	Carey RACF												
Ruby	Flare DC												
Sharon				Peregrine GH									
Shirley													Many Hands CC
Stella											Hillcrest CC		
Tilda	Crescent RACF & CC												
Tash	Harvest DFR & CC												
Vic	Harvest DRF & CC												

Appendix E. *What the **** is Normal?*¹

Impairments, limitations and trauma

I made notes about the study's 29 participants after our first meetings. I recorded that one person had a habit of twisting her fingers when she talked. Another I called Laurence because he reminded me—both physically and temperamentally—of Peter O'Toole's Laurence of Arabia, and a third seemed like a slightly sad air hostess from the seventies. I did not focus on impairments, though some were apparent and some people told me about them. Some had been a fact in the person's life from birth,² though their manifestations had changed with maturation. Most were compounded or relieved by external circumstances, including life chances. Clients were eligible to be in the study because workers were assisting them with the tasks of daily living. Thus I expected them to have any of a variety of impairments, and that some might experience a number. So it was: a participant who had had a stroke which resulted in being unable to walk was also diabetic and had increasingly failing kidneys. For another, the accident that resulted in receipt of a support package was only the latest in a long series of illnesses and other traumatic events.

But distinctions between workers and clients based on capacity or incapacity were arbitrary and constructed (for a useful discussion on this, see Kumari-Campbell, 2009). The study's 29 participants reported such things as loss of sight, cancer requiring major surgery, brain injuries through accidents, illnesses or strokes, other physical injuries requiring surgery and hospitalisation, debilitating episodes of mental illness, congenital or genetic conditions, significant personal trauma (such as the death of a partner, spouse or child), experiencing sexual or other abuse, and living with a partner or child with

¹ This is the title of Francesca Martinez's (2014) autobiography.

² They are not, for that person, 'abnormal', as Martinez (2014) points out.

serious illness or significant disability. There was a person whose clothes hid severe childhood injuries, and another who had both a well-managed degenerative disease and had lost several family members in a traumatic way. The conditions participants talked about are listed in Table A.2. But the participants with these experiences and conditions were not all ‘clients’. Workers gradually revealed their own experiences of physical or psychological injury.³ Some workers were dealing with major illnesses and traumas and some clients—at least partly because of the quality and quantity of support they received—were thriving. Further, the data suggest that for some workers, the ‘care yardsticks’ they spoke of were the product of personal experiences of illness and trauma.

Table A.2. Participants’ experiences of trauma and impairment

Condition reported	Clients affected	Workers affected
Significant impairment to sight	3	2
Cancer (requiring major surgery)	2	2
Brain injury	3	1
Injury requiring surgery	2	4
Episode of serious mental illness	None reported	3
Congenital or genetic condition	3	None reported
Degenerative disease	1	1
Significant personal trauma	3	3
Significant experience of abuse	3	1
Partner or child with significant illness or impairment	1	3

³ It is possible that workers’ experiences of injury and illness were under-reported, as these impairments were not a focus of the study. As well, in some cases, the existence of significant trauma for workers was reported by their dyad pair, and not by the worker themselves.

Note: Where a single condition results in several impairment outcomes, only the primary condition is counted. Where conditions or injuries and impairments are the result of separate insults, they are recorded as separate events.

Appendix F. Photo prompts

The 67 photo prompts were printed A4 size with the source on the reverse. Each image took up the entire page. Prompts were laminated. Participants could respond to whichever and however many they wished.

Disability
expectations
Investing in a better life, a stronger Australia, 2011



Disability
expectations
Investing in a better life, a stronger Australia, 2011



National disability strategy 2010-2020



Living better. Living longer 2012 Falls



EBLL 2012



EBLL 2012



Cyfa newletters



NDIS promo





Care workers rise as secretaries gone

- by: Rachel Barendse
- From: [The Australian](#)
- January 31, 2013 12:05AM

AGED-CARE workers Georgia Holton and Robin Fuller are part of the fastest-growing occupation in Australia, while secretary Valerie Bule is part of a dying breed.



More News

Aged care wage push goes to Canberra

by Simon Benson

From: *The Age*

February 08, 2012 11:00AM

Aged care workers are mostly women who are some of the lowest paid in Australia. Source: AdelaideNow

MORE than 300,000 low-paid aged care workers will today launch a push for an \$8 an hour pay increase.



The Australian

From: *agribusiness and News Limited publications*

National Breaking News

'Not enough cash' for aged-care wage rise

by: *By Adam Bennett*

From: *AAP*

March 05, 2013 4:10PM

The government will spend \$1.2 billion to help lift the minimum award rate for aged-care workers. Source: *AAP*

AGED-CARE providers say \$1.2 billion from the federal government will be nowhere near enough to kick-start a threefold expansion of the sector's workforce by 2050.



Agel and community care, Townsomba



Minnes Valley Leader:
From Sudan to Avondale Heights to help
- People
20 Sep 12 @ 10:15am by Lish Ly
Betty Mujak with residents Yolanda and Alice.



DPS guide images



'Acute shortage' of ethnic aged care workers
26 OCT 2012, 8:35 AM - SOURCE: BWA KIMAN, SBS
There is an acute shortage of aged care workers with the language skills to cope with the growing ageing population in Australia, ethnic aged care providers have warned.
Ethnic aged care providers are urging the federal government to allow in temporary workers with European language skills.



EUREKA STREET, THE AGENDA
Aged care dirty work done dirt cheap
MICHAEL MULLINS APRIL 28, 2013



Oak Tasmania web site: 19th February 2013: Oak's Men's shed Tutor Omar Venegas (left) with Christopher Mizzitis & Michael Ramsley.



Parasol NSW
Parasol has been providing home-based personal care services since 1986. Our experience, dedication and person-centred approach ensures our service is one of the best in the industry.



A caring role
August 6, 2012 | ben.dietrich@assembly



Brochure illustration, for training organisation: nh&ts
<http://www.nh&ts.org.au/Pages/home.aspx>



St Ann's residential services:



CBS photo gallery



CBS photo gallery



Web sourced



Web sourced



Web sourced



Web sourced



with source



<http://inkabouish.wordpress.com/category/health-and-safety/>



Equipment <http://prdyredmond.blogspot.com.au/2012/09/personal-protective-equipment-gpe.html>





[The Reckoning](#)
Balancing the cost of care
Article by [JIM SPENCER](#), Star Tribune
Updated: March 22, 2013 - 2:42 PM



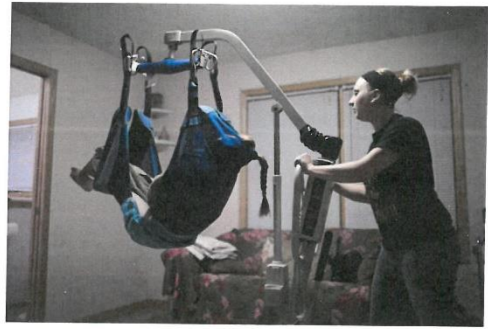
The Beckoning
Balancing the cost of care
Article by [Jill Stenicek](#), Star Tribune
Updated: March 22, 2011 2:42 PM



Balancing the cost continued



Balancing the cast continued



Balancing the cast continued



Methodist Welfare Society: Care by feeding
By: Chung Bing Han
January 3, 2012



Avivision.org
Feeding the Elderly: A Labor of Love
Posted on December 26, 2012 by Amy Sessler Powell



Mobilityaids.blogspot.com.au



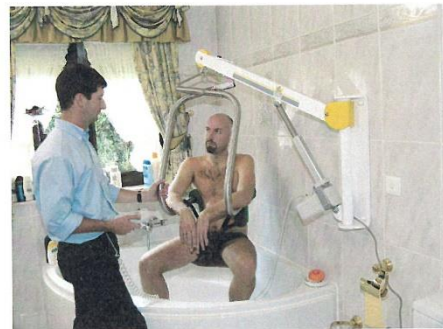
Tinytrails.blogspot.com.au



http://www.zebley.org.uk/show.php?src=10&category_desc=BathroomEquipment&area_id=1&area_desc=All%20Mental%20Health%20Services&area_id=1&area_desc=All%20Mental%20Health%20Services&area_id=1&area_desc=All%20Mental%20Health%20Services



<http://www.nrs.uk.co.uk/hand/move-body-support.html>



<http://www.nrs-uk.co.uk/handimove-body-support.html>



Mobilityaids.blogspot.com.au



http://www.candoability.com.au/CDA/Blog/Wheelchair-Hoist-For-Sale_89.html



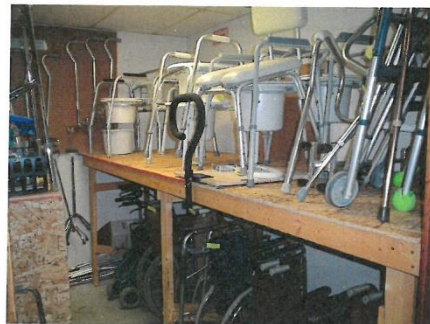
<http://101mobility.com/blog/wp-content/uploads/2013/03/iiko4.jpg>



Brimbank City Council inclusive sport:
http://www.brimbank.vic.gov.au/Parks_and_Activities/Our_Letisure_Services/Sport_and_Recreation/inclusive_Sport_for_People_with_a_disability



http://www.stoughton.wi.nz/index.asp?type=8_BASIC&SEC=6787288C765-33A7-4630-AB07-ED96CEFA5C50N20



http://ncj-dnrhomemcare.co.uk/?page_id=25



Home Care Challenge: Retaining Workers, Keeping Costs Low

By COLLEEN SHADDOCK | February 18, 2013 (<http://c-hi.org/2013/02/18/home-care-challenge-retaining-workers-keeping-costs-low/>)



<http://www.localhomecareproviders.com/blog/pays-care-home/>



National Equal Opportunities Network



National equal opportunities network, new zealand



<http://www.undis.org/services/home-health-care.php>



Inner east community health (Australia)



- [Mirror.co.uk](#) by [Jason Beattie](#)
- [Comments](#)

£500m funding gap leaves elderly care in crisis

[30 Jan 2012 00:01](#)

Elderly people could go without basic care because of a £500million funding crisis, a report warns today.

Check out all the latest News, Sport & Gossip at [Mirror.co.uk](#) <http://www.mirror.co.uk/news/uk-news/500m-funding-gap-leaves-elderly-care-in-crisis>
5583186xaz275qaz26
Follow us: [@DailyMirror](#) on Twitter | [DailyMirror](#) on Facebook



<http://www.helpinghandshomecare.co.uk/Training-and-development.aspx>



<http://www.caretalkbusiness.co.uk/features.php?page=features&article=298> lady takes on the UK's top care
Friday, 16 November 2012



<http://www.manutention.org.au/content/9/What-is-Manutention.aspx>



Indian Link: <http://www.indianlink.com.au/front-page/help-with-aged-care-homes/>



National equal opportunities network, new Zealand



ADQ Journal online (doctor and client)



Here is Wendy last Friday with Sharon Morrison, her 'Personal Care Worker' – a lovely young lady who really cares for and about her. We are very fortunate to have such a splendid helper to take the load off my shoulders. We also have various other professionally qualified staff, nurse, physiotherapist, occupational therapist, from the Community Care Akasia Centre who see her here at home, and a large team of dedicated experts at the ALS Clinic. Between all of them and an array of assistive devices, our lives are manageable. It is just as well we have abundant help because Wendy's condition is progressing, slowly but relentlessly.

http://lastwords.blogspot.com.au/2010_06_01_archive.html



Akasia training web site (aged care worker) http://www.akasia.com.au/?page_id=19



Aladia training web site (disability support worker) http://www.aladia.com.au/?page_id=19



<http://www.jahpointme.com/services/train-for-a-jah/fetated-oume-descriptions>



Appendix G. Interview protocols

Two types of interview were conducted:

- All participants were interviewed at the start of the project to share information about the aims, schedules, photo-elicitation (describing purpose and techniques and providing cameras to the dyad participants), worker and recipient demographics, etc.; and
- Follow-up interviews (longer duration) sought more in-depth information and used photo-elicitation (using images that are participant-created, public, or both) to explore themes derived from the research questions and from (any earlier) interviews, observations and analysis of public images.

Indicative interview outlines for these interview types are set out below.

Interview 1: up to 30 minutes

Interview 1 is a familiarisation, 'vibe' checking, demographics gathering and contact scheduling session, which will include the following activities:

- Interviewer (Susan Banks) to explain the project.
- Discussion of the content of the information sheet and respond to any questions.
- Talking about consent and privacy, and gain consent.
- Commencement of audiorecording (if appropriate) or note taking.
- Talking about public images of the work [open discussion of this] and introduce the idea of creating own images [dyad participants only].
- Providing camera [or schedule time to provide] and setting date for next meeting/second interview.

Guiding question [workers]: Tell me a bit about yourself and how you got into this work ...

Guiding question [recipients]: Tell me a bit about yourself and about the services you get ...

At completion, Susan will:

- Thank the participant.
- Provide a card for contacting the researcher (with photo), with next interview [or observation/meeting] time and place on back.

Subsequent interviews (and informal conversations)—Workers

The following topics are indicative (and will be developed in response to data gathered from participants) and will be discussed over the course of the second, and subsequent interviews:

- Topic: Workers' perceptions of themselves in this role.
- Topic: Workers' perceptions of their clients. How do workers construct their clients—dependent, interdependent, independent with help? What are the stories workers tell about their clients and their clients' condition, or other aspects of the client's life?
- Topic: Practice. What workers do
- Topic: How is the work seen by others? [Photo-elicitation using public, media/policy and organisation documents and images]
- Topic: How workers see themselves doing the work [Photo-elicitation using participant-created images]
- End of interview/conversation

I'm just wondering if there is anything else you want to mention or talk about.

Discussion of next meeting/observation time/collection of camera, etc.

Thank you.

Subsequent interview/s (and informal conversations)—Recipients

- Topic: Recipients' perceptions of the workers (not only the one in the dyad).
- Topic: Clients' perceptions of the work.
- Topic: Practice. What workers do
- Topic: How is the work seen by others? [Photo-elicitation using public, media/policy and organisation documents and images]
- Topic: How recipients see the work [Photo-elicitation using participant-created images]
- End of interview/conversation

I'm just wondering if there is anything else you want to mention or talk about.

Thank you.

Appendix H. Project reports

Report 1, August 2013

Stories of support and care—exploring practice and meanings of care for workers providing services to people with disability or the frail aged

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The story so far ...

Since May 2013, I have been gathering the thoughts, experiences and opinions of workers who provide—and people who receive—care and support across the southern part of Tasmania. I set out with the hope of

including about 15 workers in the project as well as 8 recipient and worker pairs. The questions I am being guided by are listed in the box.

Twenty-one people are in the study at present, about two-thirds of them are people working to provide care and support and the remainder are older people and people with disabilities who live in facilities or in the community. All these people have been amazingly generous with their time and their thoughts, as well as being wise, interested, 'personable' and sometimes very funny. I am finding this really enjoyable and stimulating!

How care and meaning meet/merge/intersect in the work of support or care workers delivering services to frail aged and disabled people.

To probe a bit deeper, I started with three things I wanted to follow:

1: Workers and work/workers and identity

How do care/support work and identity intersect for those delivering services?

2: Perceptions/depictions

How is care/support work depicted in public documents and the media?

Can participant generated photographs be used to elucidate the meanings of the work and of care for workers?

In which ways do public and worker depictions coincide?

3: Clients

Does client type make a difference to workers' perceptions of the work and themselves? OR: How do care workers perceive their work and clients? How do public depictions describe the work? What is the tension between the two?

What am I hearing and learning?

Well, the most striking thing is that the workers who are in the study are *incredibly dedicated*. This is the first of the themes I am finding—I have observed and been told about (by both workers and recipients) numerous instances of workers and

recipients doing things which are either a little bit or a lot outside the rules. These workers do MUCH MORE than they are paid to do, and care a lot more for the people they work with than 'professional boundaries' would allow. They celebrate the good things that happen for the people they work with—sometimes things which might seem

minor, like having a conversation with a person with dementia:

And it's absolutely, absolutely magic just to have him interact.

There are workers who willingly give recipients their mobile phone number, so the

recipient can call them if they need help or information:

Fred: both Joanna and Blanche have given me their mobile numbers. If, if I get into any sort of trouble, or any sort of hole – e.g., with André [a pet] – I'm to ring them. And they'll be here.

S: Okay. Okay.

Fred: Which again is a no-no ...

Then there are workers who stay that bit—or lot!—longer than they're paid for, to make sure that everything is going to work for the recipient:

Sally: I mean they often give me an extra ten minutes or so. I don't know why, but they do. You know, stay back and give us a hand.

The worker Sally was referring to regularly stays more than an hour longer. I've watched as workers arrive with special pots from home to make a particular dish, or with gear they've bought specially to make moving furniture easier. I haven't met one worker who hasn't mentioned changing light bulbs (tch-tch):

Bill: But, there are so many caveats on what Brian can and cannot do, that it turns out that he can't do the things that [my spouse] can't do. [S laughs]

S: Like changing a light bulb?

B: Well yes – absolutely. And if Brian does, it's done by some sort of osmosis, that he doesn't have anything to do with.

... or getting up a ladder to reach something in the top cupboard (dear me!). Workers might do some haircare—colouring or cutting—because they are so used to doing their own and can't see the harm. It's against the rules, but workers want to do what they can:

She still likes to dye her hair. And um, I'm quite comfortable dying hair—I've got ... teenage daughters that I've dyed hair for and I've been dying my hair for ever, and so

I was really rapt to dye her hair for her and set it, and put it in curlers and blow wave it. And it made her—I know cause of the sort of lifestyle she used to live—made her feel a million dollars!

Some workers have stayed overnight (unpaid) to make sure the recipient is okay after some medical treatment, because the service they work for doesn't offer that support. And there are those who take recipients out to the movies, or to concerts, or who invite recipients to their place for Christmas.

And recipients too are generous and rule-breaking. Some buy little presents for workers, or for workers' children or grandchildren. They care about workers' pets and might get a special food or other treat for the dog or cat. And they share their life stories and knowledge, offering advice, wisdom and moral support:

And I mean there's some, there's obviously some clients who I just go in there, do my job, and walk out. But there are others who I, I can learn so much from them.

So that's Theme 1: going outside the rules because this is not a clinical, cold relationship.

A second thing that is prominent is that touch really matters. I didn't start off thinking about this much, though I assumed that whether a worker was gentle would be important, and that I would see something about the relationships and attitudes between workers and recipients reflected in the way they touched one another—the signals of extra consideration this sent:

You know, I used to give her a bit of a shoulder massage and things like that in the shower, and just give her time to just stand ...

So, I've seen workers greet recipients with a wonderfully warm hug, kissing recipients on the cheek as they leave, touching recipients gently as they talk:

Fred: Um, I do enjoy it. I, I like the feel of someone, just putting a hand on my shoulder, or ...

S: Yep.

Fred: I feel I'm connecting with people.

Recipients value this so highly, it might sometimes seem more important than the dusting or the cooking! And recipients too want to show they care:

Stella: Anyway, and when I went back to see Ivan the next time after I'd been ill, I came through the door—cause I'd been off work for a couple of weeks—he had bolted across the room and thrown his arms around me.

S: Oh, wow!

Stella: Yeah. Wanting to know if I was okay. Isn't that nice—it was so lovely!

Theme 2: touch is important

Both in talking with workers and in watching workers and recipients together, laughter and humour have been really prominent.

Workers tell stories of their working days which are full of funny events, self-deprecation and joking about things that one might otherwise cry about. And when workers and recipients are together, there are lots of funny moments, where the two seem to share real joy and happiness:

I could walk in there and there wasn't one resident I couldn't walk past and not know their name, know their triggers, know what—you know what they like, know how to placate them when they are angry. Not one resident that was in there that I couldn't put a smile on their face.

That humour plays a role in the relationship is **Theme 3**.

Finally, for now, wages and rewards. A few recipients have talked about the pay, and worried that it is not enough—especially when workers stay longer and do extra. And they worry that some employer organisations don't seem to value workers, or have conditions attached to the work which cost the workers unpaid time or travel. This has not been mentioned much by workers, which is interesting, but workers do mention that they are sometimes not listened to in their organisations—that the knowledge they have of recipients and their needs can be ignored or discounted. Workers often want to:

Jo: Be a voice for them...

S: And do you—do that somewhat now? I mean you must do ...

Jo: Ha—somewhat—but, um, there's so many protocols at work as well, um, we have to seek permission to be able to use our voice for them.

So, wanting their **expertise and engagement to be valued in the organisations** is **Theme 4**.

So, these are the first themes I am noticing as I listen to the interviews (27 so far) and transcribe and then read them. There is more to come!

All the best,

Susan

Report 2, September 2014

Stories of support and care—exploring
practice and meanings of care for workers
providing services to people with disability or
the frail aged

1st September, 2014

Analysis and writing ...

Since May 2013, I have been gathering the thoughts, experiences and opinions of workers who provide care and support, as well as of the people who receive those services. I have had multiple conversations with 29 people, 17 of whom are paid workers. The questions I was being guided by are listed in the box. These questions are now guiding my analysis of the more than one hundred pieces of data I have gathered.

This project is exploring the practice and meanings of care for workers providing services to people with disabilities and the frail elderly. The aim of the study is to find out more about the working lives of people involved in care and support work in facilities and in the community with people with different needs. I am hoping to build up a rich, 'warts-and-all' description of the work, from the perspectives of both workers and the people they work with.

Three questions are guiding the research and the analysis:

1. *How do work and identity intersect in the delivery of support and care services?*
2. *Does client* type make a difference to workers' perceptions of the work and themselves?*
3. *How is the work depicted in public documents and the media?*

* I am not comfortable with the terms 'people with disabilities', 'frail elderly', or 'client'. I have thought about 'recipient', 'consumer', 'supported person' ... but none of those terms is accurate. Where possible, I am only using people's pseudonyms, without the tags 'worker', or '...' Any suggestions welcome!

I am very grateful to you all for letting me peek into this world, and ask my sometimes stupid questions, sometimes quite badly. Everyone has been

amazingly generous with their time and their thoughts, as well as being wise, interested, 'personable' and sometimes very funny. There have been several "Aha!" moments for me sparked by an insightful comment by a participant. Now I have to do justice to all that data and all of you in the thesis.

Who have I heard from and what has stood out?

I know that the people in this study are not a 'random sample'. You talked to me because you were interested, concerned, angry, friendly, proud, wanted to be heard ... There are other people out there who would have told a different story.

Dedication

What I have seen and heard showed me very early in the project that workers are often *incredibly dedicated*. Many do much more than they are paid to do, and want to make a positive difference to the physical and emotional wellness of the people they work with. As well, they often get *emotionally involved* (which is usually against the rules) and this has both benefits and costs for them. The people they support, too, can be emotionally engaged. It appears that in at least some cases, this emotional connection is very important. This has implications for training, worker selection, rostering, how workers are supported, and for other organisational decisions.

Other people researching workers in this field have reported that family-like relationships can develop. Researchers call this having 'fictive kin'. I have also found this, but it is certainly not what everyone wants.

Being there

The key other thing that seems to matter is that workers are 'present'. That is, people appreciate workers who are mindful of *what they are doing* and *who they are working with*, rather than being detached and automatic in the way they work.

What did you say about organisations?

Organisations have received mixed reviews. Some of the comments made related to particular people in particular roles (rostering and case managing, for example); some are related to larger processes like how attentive and responsive organisations are to workers' and clients' calls and requests. While they may be engaged in providing care and support work, some organisations are not being praised for caring about clients—or workers. But participants also recognised that organisations have to manage in tight economic circumstances.

I expected to hear more about wages and conditions than I did. Workers tend to comment that the wages are not high, but this in itself doesn't appear to be a problem. More difficult for them to accept is when there are measures put in place which cost them in other ways. Travel reimbursement limits are one example of this, as is rostering which results in trips that are long and costly and cannot be claimed for. As well, it is common for

workers to have to grab snacks and drinks on the run.

It's not supposed to be Home Beautiful ...

Finally, for now, a theme that is coming out of a large number of the interviews, conversations and observations is that sometimes 'bad' workers and 'careless' organisations have rules which change people's homes or rooms into mini-institutions. The small ways in which we shape our environments to suit ourselves—like whether clean towels are rolled or folded when put away, or whether mugs and glasses are put away rim down, or rim up—are sometimes ignored. People who commented on this were clear that they like workers who have a 'live and let live' attitude. And workers who thought it was important to not impose their own rules on the people they support also seem to like their work more. They also seem to be people who don't dwell on the 'yeuch' stuff in our lives and just get on with it.

So, these are the themes that are coming out as I do my final analysis of the material. I expect to have written a full draft of my thesis by the end of December, and will be able to report in more detail after that. I've spoken at a couple of conferences and have an article coming out in an international journal. These have been about particular aspects of the research: workers going the extra mile, about how care and support are understood by different people, and about the importance of respect in the work.

All the best,

Please remember that no person or organisation will be identifiable in my thesis, articles or presentations. I have gone to considerable lengths to mask the identity of people, places, and organisations.

I will be reporting in a very general way to all organisations in the state and none of them will know which organisation or person I am talking about.

Appendix I. Examples of observation map and sketches

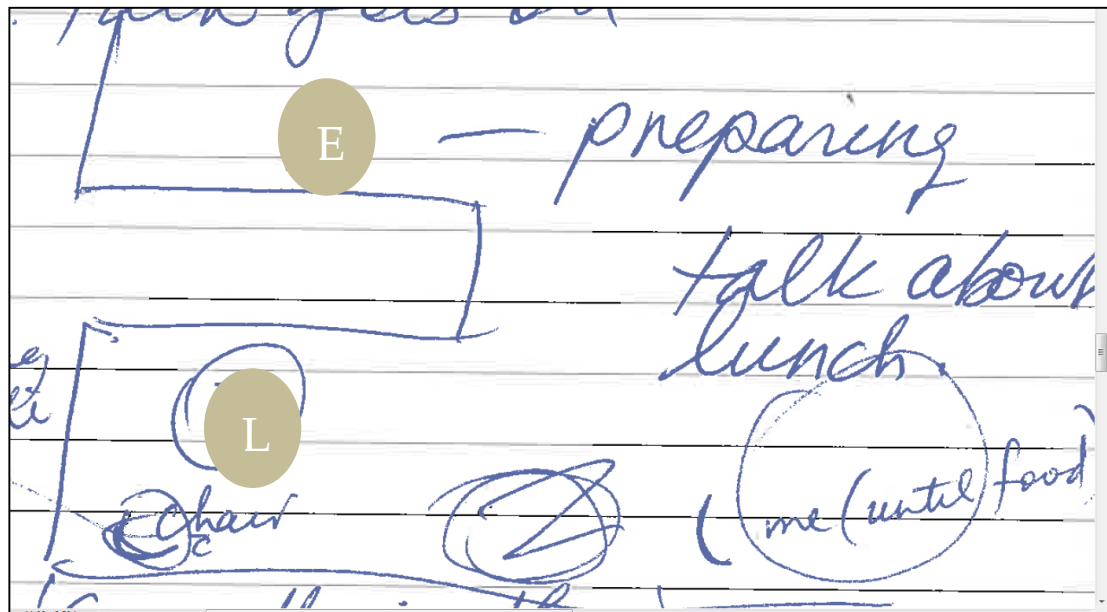


Figure AI.1. Detail from field notebook, showing map of room with positions of actors marked

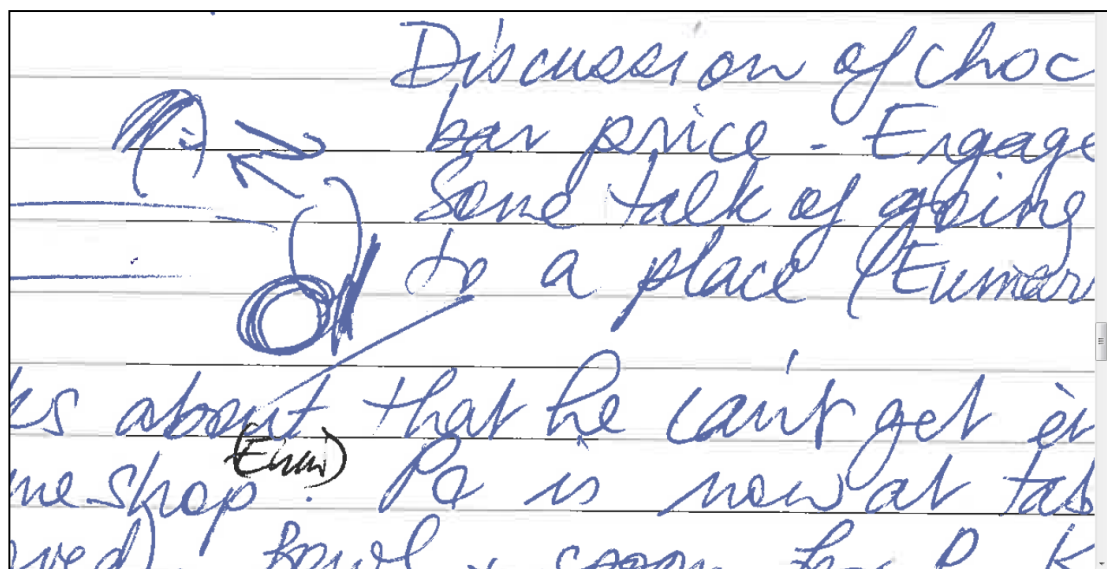


Figure AI.2. Detail from field notebook, with gaze of actors marked

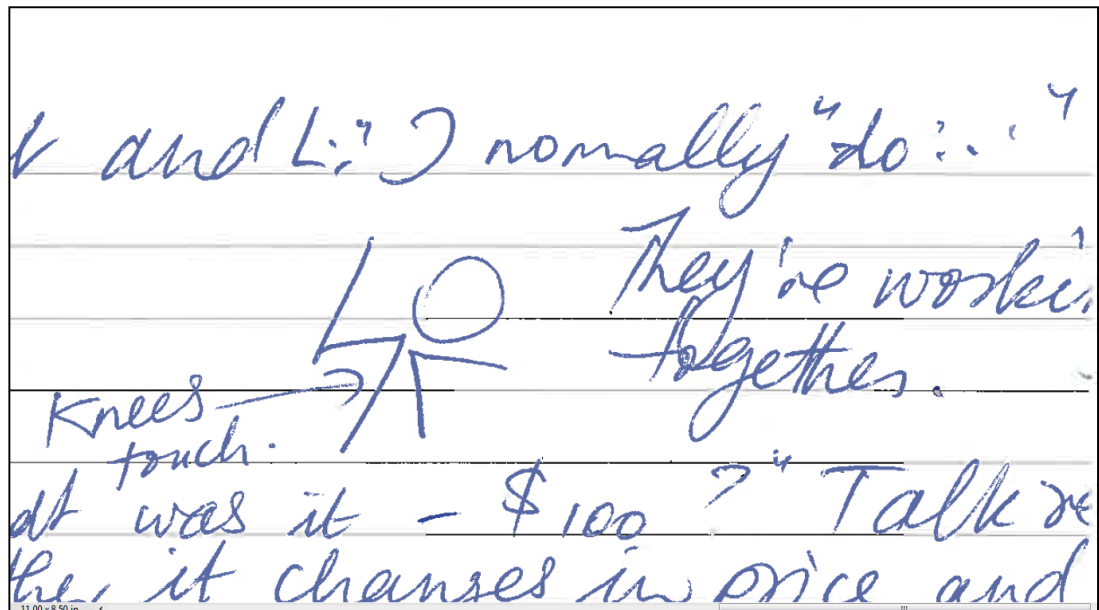


Figure AI.3. Detail from field notebook, with touch of actors shown

Appendix J. Example of an audio note

This note was recorded while driving to visit Nicko.

Thinking about going and seeing this particular participant (Nicko) who has an acquired brain injury—and then thinking about the other people I’ve spoken to and the kind of strange complexity it throws up for me who is supposed to be, um, you know, for want of a better word, ‘normal’. Certainly in a better, in a, in a, in a more middling position in terms of hegemonic masculinity slash femininity.

So I guess, I’m, I’m actually quite confronted, might be the word, by the fact that there’s—in terms of people’s needs—there’s this massive, massive array and to describe someone as a person with disability is kind of pointless. I’ve thought this before: that there is no person with disability or there is all people with disability—including old people, young people, whatever. And so the whole hegemonic, or you know, white hegemonic male discourse thing is kind of even more interesting because none of us it fitting into it, I suppose.

And so going and talking to this guy with an acquired brain injury and comparing him with [name] who has CP, or with, um, the people Vic talked about ... um, or with Fred, or Olivia, or Sally, they’re all just people who don’t quite, um, tick all the boxes for a “full human”—and I know that sounds, I don’t, I don’t think that, because I don’t think any of us ticks all those boxes, but for me there’s this sort of sense that maybe I’m coming into their life as if I am a person who ticks all the boxes. And I think that’s a kind of ridiculous standpoint and I haven’t, ah, I don’t think any of us is in that situation, so ... what’s the deal with writing about so-called disability or the frail aged or whatever, where people don’t position themselves other than as this, um, neutral, wise person who’s coming in um, and you know, just listening. And just doing this, and being totally scientific and detached; I think it’s bullshit. And I think it needs to be stated that in fact in all these situations, I am just a variant of them—they are just a variant of me. Vic is quite clear about this, you know, and a couple of the others: “there but for the grace of god”, or, not quite those words, but “It could be me!”. And in many ways it is me. They’re just, they just vary from me in some way. With the guy I’m going to see now, he has a brain injury which means that his memory is shite. He’s also got a little bit of paralysis on one side. So, hah—but I can only say that if, compared with ... somebody else. And, ah, where’s the variation start and finish? I’m just kind of thinking around this idea that I go in there and I’m supposed to be somehow above it all and I can’t possibly be. And maintaining a sort of scientific position is not possible and pretending that somehow I’m neutral is not possible. Um, I think you can do it, but I don’t know that that’s a reasonable thing to do with people who are—and I’m including the workers in this as well—ah, I don’t think you can justify doing that in a situation where you are from a different

social status than they are, and they're doing something for you. I guess that's where my funny feeling comes from ... or part of it anyway. Okay.

After the interview with Nicko, I again recorded notes.

Just thinking about Nicko, um, and his um, his whole manner. So he's, he's really—is he in the category of “I’ve been allowed to do these things”? Cause he did use the word “Let” when he was talking about Leonie letting him do something. But I didn’t get the impression that she had any, in a way, any oversight of, or letting thing going on. My feeling about her was rather the reverse; that he, he had sufficient, um, memory or sense of himself as how he’d been before, to want to do stuff. So he was proactive in a way that the people with intellectual impairments that, or intellectual disability in the Abbott and Burns (2007) paper don’t have. Um, or might not have.

There was, there’s a sense about him that he’s just going to go for it, and that includes things he hasn’t done before. So I didn’t, my impression is that ‘let’ in that case wasn’t, um, the same as in the Abbott and Burns – where it’s a sort of ... “Oh, yes, you’ve got permission to do this and it’s very bounded”. I think the only boundary that I hear from Leonie and from Nicko is, is it going to be safe for him to do that? Ah, and in fact, as a group, it sounds like they’ve stood up for him or together against some kind of not so good, um, possibilities. So, I don’t know ... and it’s interesting as well in terms of Laurence, because he very distinctly was saying to me that he wanted his worker to be like a mother sometimes. I found that really interesting and I think it entirely makes sense — because we do want that. And he might just be able to say it when most of us feel pretty ashamed of saying it, or pretty much like we shouldn’t want that thing. Anyway.

Appendix K. News stories about support and care

Articles were gathered from local and locally available mainland newspapers as well as from the Australian Broadcasting Corporation's online news site. They are listed in date order, from oldest to most recent, and referred to in Chapter

4.⁴

	Article	Reader 1	Reader 2	Reader 3
1.	Equal-pay push lands workers big rise. Ben Schneiders. <i>The Age</i> (online), 1 February 2012.	Positive, fairness, pay-rise as luck ('lands') not necessarily deserved	Fair	Positive
2.	Historic day as gender pay gap narrows. Big win for community sector workers. Ben Schneiders and Michelle Griffin. <i>The Age</i> (online), 2 February 2012. [Photo: small group of smiling women being interviewed; photo: Seven smiling women looking at camera over fence. Caption: Women's health workers (left to right) Pip Robertson, Cath Lancaster, Toni Bentley, Anna Stewart, Helen Riseborough, Sandra Morris and Kei Judd celebrate the equal pay ruling]	Gender, positive, fairness, pay-rise as luck (undeserved)	'you beauty', pay-rise a good thing	Positive
3.	Aged-care sector may be first to exploit landmark ruling for community workers. Unions plan equal pay expansion. Ewin Hannan. <i>The Australian</i> , 2 February 2012, p. 1.	Exploit = not quite kosher, thin end of the wedge (i.e. others will start demanding)	Exploiting, greedy unions will ask for more	Triumph
4.	Risk that others will want more. Judith Sloan. <i>The Australian</i> , 2 February 2012, p.1.	Negative, greedy (that workers are being greedy)	Open the floodgates – other workers will start demanding more	Problematised, delegitimised

⁴ Story headlines are presented first, then author, source and date.

5.	Aged care set to lead next wage push (continued from page 1). <i>The Australian</i> , 2 February 2012, p. 2.	Risk (to the economy), thin end of the wedge of demands	Open the floodgates – other workers will start demanding more	Vanguard
6.	Reasoning behind carer hike spells danger for the economy. Judith Sloan. <i>The Australian</i> , 2 February 2012, p. 2.	Risk, watch out, economy endangered	Wrong reasoning, Fair Pay Commission wrong	Problematised
7.	More money shows respect for workers. Stephen Lunn. <i>The Australian</i> , 2 February 2012, p. 2. [Photo: Young woman standing in copse of large trees. Caption: Mental health worker Jaina Devlin says yesterday's decision on equal pay will make it easier to keep staff in a demanding and difficult job]	Respect for workers	Respect for workers and old people	Recognition
8.	Warning of flow-on pay claims. Ewin Hannan. <i>The Australian</i> , 2 February 2012, p. 2.	Risk to everyone or economy from this change	Watch out, we're doomed now	Neutral
9.	Equal pay milestone. Nick Clark. <i>The Mercury</i> , 9 February 2012.	Positive, gender fairness	Positive	Historic
10.	No care for the aged. Frail, elderly at risk after state misses out on federal help. Jennifer Crawley. <i>The Mercury</i> , 8 March 2012, p. 3.	Aged care is a site of risk, vulnerable people	Feds don't care	Problematised
11.	Tassie joins pay rise bid. Michelle Paine. <i>The Mercury</i> (online), 9 February 2012. [Photo: Smiling middle aged woman in uniform at doorway of house. Caption: Aged-care worker Jannette Clark, of Gagebrook]	Neutral	Neutral	?
12.	Concerns on dementia care. <i>The Mercury</i> (online), 27 February 2012.	Risk – dementia is scary, care is not adequate	Epidemic, panic	N/A

13.	Disability groups hail \$3bn insurance plan. Sue Dunleavy. <i>The Australian</i> , 2 April 2012, p. 4.	Good, a lot of money	Positive	Support?
14.	Disabled Australians look forward to a better deal. The government has much to do to implement an NDIS. Editorial. <i>The Australian</i> , 2 April 2012, p. 13.	Fairness for this group	All good, devil in detail	WTF
15.	Fast-track disability plan a 'cruel hoax'. Funding brawl as power shifts in federation. Imre Salusinszky and John Ferguson. <i>The Australian</i> , 2 April 2012, p. 14.	Constitutional risk?	Don't trust the government	
16.	Give us dignity. 54,900 People aged over 70 in 2010. 101,688 People aged over 70 in 2027. Aged care advocates say it is now time for action. Sally Glaetzer and Jennifer Crawley. <i>The Mercury</i> , 3 April 2012, pp. 1, 4.	Tsunami, risk, vulnerable people	Mendicancy proved by numbers, have no dignity	
17.	Call for dignity in aged care crisis (from page 1). [Liftout quote: 'Hospitals are the worst place for old people'] <i>The Mercury</i> , 3 April 2012, p. 4.	Risk, old people vulnerable	Vulnerability, victims, there is no dignity now	
18.	Long wait for home care affects health. Jennifer Crawley. <i>The Mercury</i> , 13 April 2012, p. 11. [Photo: Woman with electric kettle and two tea cups in lounge room, with younger woman seated at dining table behind her. Caption: Difficulties: Muriel Sproule attempts to make a cup of tea for her aged-care advocate Hilary Brown.]	Vulnerable victims	Passive people	
19.	Care the key to ending aged 'hell'. Adele Horin. <i>The Age/National Times</i> (online), 14 April 2012.	Risk, vulnerable people	Passive people	
20.	Gillard's \$3.7 billion aged-care reform. Jessica Wright and Judith Ireland. <i>The Sydney Morning Herald</i> (online), 20 April 2012. [photo prompt]	neutral	Neutral, positive?	
21.	Home is where the heart is, and older citizens stay put. Rachel Wells. <i>The Age</i> (online), 20 April 2012. [Photo prompt. Caption "Marjory Chamberlain at home with aged-care worker Dianne Bradley"]	Stay home, positive? Neutral?	Independence, not unequivocal, (people) can't do it alone	Respect

22.	If you think the disability insurance scheme is not your problem, think again. Ever thought how much it would cost you if a family member became disabled? Elizabeth Manning. <i>The Age</i> , 26 April 2012, p. 15.	Risk, fairness	Call to action, there but for the grace of god	
23.	With better digs comes a happier life. [Liftout quote: 'I put on a brave face for my parents but deep down I wanted to burst into tears']. Kate Hagan. <i>The Age</i> , 27 April 2012, p. 3. [Photo: Young woman in electric wheelchair. Caption: Multiple sclerosis sufferer Katy Skene, 31, counts herself fortunate for having left an aged care facility for better accommodation]	Powerless, victim, passive	Stuck with mendicancy, long-suffering	
24.	Shifting fortunes for disabled. Stephen Lunn. <i>The Australian</i> , 27 April 2012, p. 6. [Photo: Young man in electric wheelchair in garden outside house. Caption: Adam Greaves has left a nursing home under a government program to move younger disabled people out of aged care]	Positive but powerless, passive	Stuck with mendicancy, about getting a slightly better life	
25.	Disabled to rally for new scheme. Tess van der Riet. <i>The Age</i> , 30 April 2012, p. 4. [Photo: Head and shoulders of young man. Caption: Grayden Moore]	active	Tilting at windmills, active	
26.	Aged care reforms under fire. New report blasts government plan. Mark Metherell. <i>The Age</i> , 30 April 2012, p. 5.	Risk, political	Neutral	Blame game
27.	1.2b pay rise incentive for aged care workers. Mark Kenny and Judith Ireland. <i>Sydney Morning Herald</i> (online), 5 March 2013.	Positive and scary	Better pay, a lot of money involved	
28.	Intimacy a dilemma with no real solution. <i>The Age</i> (online), 22 March 2013.	Passive?	No rights, victim but uncaring attitudes	
29.	Disabled care fails boy. Heather Ewart. ABC News (online), 1 April 2013.	Victim, care bad	Kid out of control? Care not working	
30.	No place like home: PM's aged care plan. Michelle Grattan. <i>The Age</i> (online), 21 April 2013.	Stay home = good	Cynical, cheap government	

31.	<p>Mum's lingering fear: will we be covered? Rick Morton. <i>The Australian</i>, 2 May 2013, p. 1.</p> <p>[Photo: mother with two children on playing field. Photo caption: Pat Jones, with daughter Georgie, 7, and son Ethan, 6, yesterday, wonders whether the scheme will cover Georgia, who has a rare chromosomal disorder]</p>	passive	It is worrying, mendicant	
32.	<p>Disability scheme funds to boost Swan's bid for surplus. Budget bounce from levy rise. Sid Maher. <i>The Australian</i>, 2 May 2013, p. 1.</p>	political	Give with one, take with the other	
33.	<p>Working on monuments that may never be built. The PM wants to leave her political legacies, but time is running out. Graeme Richardson. <i>The Australian</i>, 2 May 2013, p. 10.</p> <p>[Image: Pen and ink illustration of Gillard, standing on a wheelchair, sculpting a very large bust of herself using hammer and chisel, with a tool bag hanging from the bust's nose]</p>	Vanity project	Dunno, political	
34.	<p>'I don't care who does it, just make it happen'. Rosanne Barrett. <i>The Australian</i>, 3 May 2013, p. 4.</p> <p>[Photo: Smiling woman with coffee cup sitting in electric wheelchair in modern loungeroom. Caption: Hazel Morel, who has multiple sclerosis, at her home in Brisbane's west built by Youngcare to get people out of aged-care facilities.]</p>	Need, passive	Mendicant	
35.	<p>Care on a learning curve. Two million people stand to benefit but scheme still has a long way to go. Rick Morton. <i>The Australian</i>, 3 May 2013, p. 9.</p> <p>[Photo: Seven people – four adults and three children talking at picnic tables in a park. Caption: Julia Gillard and Disability Reform Minister Jenny Macklin meet a disability group after announcing details of the Disability Care levy. Photo: Man in suit standing in street. Caption: Bruce Bonyhandy, one of the scheme's chief architects]</p>	Tentative, positive	We don't know what we're doing	

36.	None of us choose this. ... it would be nice to have the quality of life others do. Duncan Abey. <i>The Mercury</i> , 3 May 2013, p. 1. [photo of smiling mother and son]	Passive, victims	Poor me	
37.	None of us choose this, says exhausted mother (continued from front page). Duncan Abey. <i>The Mercury</i> , 3 May 2013, p. 6. [Photo of child. Photo caption: Frank Gunn needs constant care because of his many disabilities]	victim	Poor me, victim	
38.	Levy rise to pass despite fears. Adam Creighton and Patricia Karvelas. <i>The Australian</i> , 3 May 2013, p. 4.	Risk	equivocal	
39.	Experts ignore on call for sole funding. Adam Creighton. <i>The Australian</i> , 3 May 2013, p. 4.	?	Politics ignores experts	Delegitimise
40.	Workers looking for career change find a more caring profession. Rachel Browne. <i>The Sydney Morning Herald</i> (online), 5 May 2013. [Photo prompt: Job swap: Nicky Bosman, with Bill and Ailsa Bernhardt, with whom she works as a carer]	Nice job	Positive, care is good work	
41.	Abbott wins support on NDIS. Patrick Lion. <i>The Mercury</i> , 6 May 2013, p. 2. [Photo: Five adults, one in a wheelchair] and a child in a room. Caption: Doubts: Polling suggests voters don't believe Prime Minister Julia Gillard, pictured at Yooralla House, Melbourne, can deliver on the national Disability Insurance Scheme]	NDIS hero	No comment	
42.	Scheme may collapse without skilled staff. Rick Morton. <i>The Australian</i> (online), 6 May 2013.	Risk, lack of skilled staff	Doomed	Desperate
43.	No, Disability Care will not cost a dollar a day. It would be better to fund this scheme and Medicare from consolidated revenue. Gary Johns. <i>The Australian</i> , 7 May 2013, p. 12.	Financial risk	Disabled stuff is costly	
44.	Death of elderly woman prompts calls to punish cruel carers. Stephanie Smail. <i>The World Today</i> , ABC News (online), 29 May 2013.	Victim, danger, cruel staff	Carers not trustworthy and nasty	

45.	Care group admits deficiencies over boy's death. Adam Cooper. <i>The Age</i> (online), 24 June 2013.	Cruel staff, victims, danger	Carers not to be trusted, not sure we should be paying for this	
46.	Frank's birthday bonus. [Liftout quote: 'No longer are we dictated to by what is available. Now they are asking us, 'what do you need to have a reasonable life'] Duncan Abey. <i>The Mercury</i> , 1 July 2013, p. 11. [Photo: Two young women (holding Wii controllers) and a boy—all smiling and apparently dancing. Caption: Joyous: Frank Gunn hangs out playing a Wii dancing game with his sister Rowena, 16, right, and her friend, Tess Nettlefold, 17]	Passive, bomus (lolly jar), lucky Frank	Lolly jar, will be taken away later	
47.	'Strong concern' over 170 patient deaths. Kate Hagan. <i>The Age</i> (online), 3 July 2013.	Cruel care	Do something	
48.	Aged care crisis. Margot O'Neill. ABC News (online), 15 July 2013.	crisis	Constant crisis, is this out responsibility?	
49.	Mistreated nursing home residents 'better off in a concentration camp'. Margot O'Neill. ABC News (online), 16 July 2013.	Victims, cruel care	The more you hit them, the less you can pay them (workers, that is)	
50.	Tasmanian aged care facility looks to fill system's gaps. Jonathon Gul. ABC News (online), 17 July 2013.	Positive, but failing system	Entrepreneurship is good	
51.	Full-time care after lifetime of fighting for others. Emma Sleath. ABC News (online), 18 July 2013.	courage	You will get rewarded but it won't be good	Struggle
52.	Senate committee recommends outlawing forced sterilisation of children with disabilities. Rebecca Barrett. ABC News (online), 18 July 2013.	passive	Incapable, need management	

53.	Aged care workers cite abuse and neglect of nursing home patients. Margot O'Neill. ABC News (online), 14 August 2013. [Aged care workers say their industry is facing a staffing crisis, with claims of abuse and neglect as patients struggle to get even basic care.]	Crisis, vulnerable, passive	Self-righteous: "it's not me; I'm better"	
54.	Nurse made patient 'beg and suck his thumb'. H. Aston. <i>The Sydney Morning Herald</i> (online), 27 September 2013. [A male nurse made an elderly dementia patient get down all fours and beg him for cigarettes, and forced a 99-year old female patient to suck his thumb. ...]	Passive victim	Nasty care, sadist, no agency for patient	
55.	Kevin Andrews defends plan to alter Disability Support Pension entitlements. ABC News (online), 23 December 2013.	Lolly jar	undeserving	
56.	Disability pensions to come under fresh scrutiny as government tightens screws. Jonathan Swan. <i>The Sydney Morning Herald</i> (online), 19 April 2014.	Lolly jar	Undeserving	Welfare cheats
57.	Elderly and disabled under increasing threat of abuse in homes, says Public Advocate. Julia Medew and Henrietta Cook. <i>The Age</i> , 18 September 2014, p. 15.	Cruel care, passive	Dangerous place, weak people, unable to protect themselves	
58.	Bill to protect disabled people from abuse is introduced into SA Parliament. ABC News (online), 29 October 2014.	victims	They can't take care of themselves, mendicant	Why do we need one?
59.	Intellectual disability groups believe the NDIS is unfairly geared to the physically disabled's needs. Julia May. <i>The Age</i> (online), 14 December 2014.	NDIS unfair	2 sets arguing about who is more deserving – look how stuffed I am, providing	
60.	'Strong welfare cop': Scott Morrison's new self-proclaimed title. Matthew Knott. <i>Sydney Morning Herald</i> (online), 22 January 2015.	Lolly jar		
61.	Government doctors to evaluate new support pension. Crackdown on disability.	Lolly jar	Undeserved	Cheats

	David Meers. <i>The Mercury</i> , 2 February 2015, p. 11.			
62.	Former Yooralla manager pleads guilty to sexually abusing cognitively impaired woman in Drouin. Steve Butcher. <i>The Age</i> (online), 7 February 2015.	Cruel care, passive victim	Not safe, in thrall of bad people	
63.	Senate to hold inquiry into abuse of disabled people following Yooralla case. Judith Ireland. <i>The Sydney Morning Herald</i> (online), 11 February 2015.	Passive, cruel care	Unsafe	
64.	Bundaberg nursing home assaults prompt call for Queensland aged care review. Emma Pollard. ABC News (online), 16 February 2015.	Cruel care	Not safe, in thrall of bad people	
65.	Abuse inquiry into Victorian disability sector to reveal 'problems on a national scale'. ABC News (online), 3 March 2015.	Cruel care	Disabled people will be fucked	
66.	Governor-General honours disabled worker for 50 years service to employer. ABC News (online), 23 March 2015. [Photo: Governor-General handing framed certificate to man; Tasmanian premier and two other people clapping. Caption: Governor General Sir Peter Cosgrove hands a certificate to Peter Harvey who started work with Oakdale Industries in 1965]	positive	Positive – singled out but okay	
67.	Disability abuse victims 'have nowhere to go'. Rick Morton. <i>The Australian</i> (online), 11 April 2015.	Passive, disempowered	Lack of power	
68.	'Voiceless' disabled 'raped, bitten, burned' while in care. Rick Morton. <i>The Australian</i> (online), 11 April 2015.	Disempowered, cruel care	Lack of power	
69.	Institutional culture fuels disability abuse, inquiry told. Rick Morton. <i>The Australian</i> (online), 14 April 2015.	Cruel care, disempowered residents	No comment	
70.	Aged Care Timebomb. 20 nursing homes, 5000 workers needed 'within 5 years'. <i>The Mercury</i> , 3 May 2015, p. 1.	crisis	All doomed	
71.	Australia not equipped to cope with growing 'tsunami' of dementia cases, advocates warn. Karen Tan. ABC News (online), 3 May 2015.	crisis	All doomed	

72.	Aged care jobs anger. Qualified workers overlooked for permanent positions. David Beniuk. <i>The Mercury</i> , 10 May 2015, p. 9.	crisis	Be afraid of unqualified staff	
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